

**Exploring the Healthcare Experiences and Quality of Life of People with Mild
Cognitive Impairment and their Caregivers**

Dr Katherine Jane Dean

Submitted to University College London for the degree of MD(res)

Declaration

I, Katherine Jane Dean, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Acknowledgements

I would like to thank all those who helped me with this research – including my supervisors (Prof Jenkinson, Dr Walker and Prof Wilcock), the research staff who helped with recruitment and BUPA Giving who funded the work. Particular thanks go to all the subjects who generously gave their time to take part in the study, without them this research would not have been possible.

This thesis is dedicated to my grandparents Daphne and Ken Agar, whose experiences of dementia and, consequently, caregiving serve as a personal reminder of the individuals behind every 'case' of cognitive impairment.

Abstract

Mild cognitive impairment (MCI) is a common condition which lies between normal cognition and dementia. Relatively little is known about the experiences of people with MCI (PWMCI) and their caregivers ('advocates'), particularly regarding healthcare services. No measures developed specifically to evaluate health related quality of life in PWMCI or their advocates exist. Therefore the aim of this work was to gather information about these groups' experiences of living with MCI, with particular reference to their contact with healthcare services, to use this information to develop a patient reported outcome measure (PROM) for PWMCI and equivalent measure for advocates and to suggest improvements to healthcare services in light of the findings. Initial, in-depth information was gathered during semi-structured interviews with 23 PWMCI and 20 linked advocates, the resulting data was analysed using grounded theory methods. Commonly recurring and salient themes from analysis of the interview data were used as a basis for initial drafts of the outcome measures and patient and advocate surveys regarding healthcare experiences. The outcome measures and healthcare surveys were combined into two questionnaires (one for PWMCI and one for advocates). These initial drafts were discussed with a focus group and refined in light of their feedback, the resulting questionnaires were administered (by post) to 280 PWMCI (recruited from research databases and memory clinics) and their linked advocates. The response rate was 54% for PWMCI and 36% for advocates. Data from the outcome measure section of the questionnaire was analysed using factor analysis producing a measure for PWMCI (the MCQ) and one for advocates (the MCQ-Carer); both had good psychometric properties. Descriptive analysis of the healthcare experiences survey data revealed that both the PWMCI and advocates reported a range of unmet needs for help, support and information related to MCI; appropriate suggested improvements to healthcare services are made.

Table of Contents

Chapter 1: Introduction	15
1.1 Thesis Structure	15
1.2 Background	16
1.2.1 Introduction to Mild Cognitive Impairment	16
1.2.2 Relevant Policies	17
1.2.3 Current Support and Information for People Affected by Mild Cognitive Impairment	19
1.2.4 Patient Reported Outcome Measures in Mild Cognitive Impairment	20
Chapter 2: A Critical Review of The Literature.....	22
2.1 Methods.....	22
2.2 Patients' Experience of Mild Cognitive Impairment	24
2.2.1 General Experiences of Living with Mild Cognitive Impairment.....	24
2.2.1.1 Cognitive Changes.....	24
2.2.1.2 Function	24
2.2.1.3 Emotional Consequences and Neuropsychiatric Symptoms.....	26
2.2.1.4 Coping.....	27
2.2.1.5 Attributions	28
2.2.1.6 Insight and Mild Cognitive Impairment	29
2.2.2 Patient's Experiences of Healthcare and Support Services	31
Diagnosis	31
Reasons for Presentation to Healthcare Services.....	32
Experiences at Memory Clinics.....	32
Diagnosis Disclosure.....	34
Information Provision	34
2.2.3 Suggested Interventions and Support	35

2.2.4 Patient Reported Outcome Measures for Mild Cognitive Impairment.....	37
2.3 Caregivers' Experience of Mild Cognitive Impairment.....	39
2.3.1 General Experience of Caregiving in Mild Cognitive Impairment.....	39
2.3.1.1 Changes Noticed.....	39
2.3.1.2 Effects on Relationships.....	40
2.3.1.3 Carer Burden.....	40
2.3.1.4 Strategies and Coping.....	42
2.3.1.5 Emotional Consequences	42
2.3.1.6 Attributions	44
2.3.1.7 Comparison With Caregiving in Early Dementia	45
2.3.2 Caregivers Experiences of Healthcare and Support Services	46
2.3.3 Suggested Interventions	47
Increased Support Needs	47
Relevant Studies in Dementia.....	47
Suggested Interventions	48
2.3.4 'Self-Reported' Outcome Measures for Carers of People with Mild Cognitive Impairment.....	50
2.4 Limitations of the Studies Discussed.....	50
2.5 Summary	51
Chapter 3: Interviews.....	53
3.1 Introduction.....	53
3.2 Interview Methodology	53
3.2.1 Development of Interview Topic Guides	53
3.2.2 Recruitment	53
3.2.3 Conduct of Interviews	55
3.2.4 Data Analysis.....	56
3.2.5 Discussion of Methodology.....	57
3.2.5.1 Advantages of Method and Methodology.....	57
3.2.5.2 Limitations of Method and Methodology	59

3.3 Interview results	63
3.3.1 Descriptive Results of Interviews of People with Mild Cognitive Impairment.....	63
3.3.1.1 General Description of Interviews	63
3.3.1.2 Challenges Presented by Mild Cognitive Impairment and Coping Strategies Developed	64
3.3.1.3 Feelings About Mild Cognitive Impairment.....	67
3.3.1.4 Attributions	68
3.3.1.5 Current Sources of Information and Support.....	69
3.3.1.6 Experiences of Health Services	71
3.3.1.7 Suggested Improvements to Services	73
3.3.2 Descriptive Results of Advocate Interviews	76
3.3.2.1 General Description of Interviews	76
3.3.2.2 Challenges Presented by Mild Cognitive Impairment and Coping Strategies Developed	76
3.3.2.3 Feelings About Mild Cognitive Impairment.....	80
3.3.2.4 Attributions	82
3.3.2.5 Current Sources of Information and Support.....	82
3.3.2.6 Experiences of Health Services	83
3.3.2.7 Suggested Improvements to Services	85
3.4 Discussion of Interview Results.....	88
3.4.1 General Comments.....	88
3.4.2 Challenges Presented by Mild Cognitive Impairment and Coping Strategies...	90
3.4.3 Emotional Consequences of Mild Cognitive Impairment	91
3.4.4 Attributions.....	92
3.4.5 Current Sources of Information and Support	93
3.4.6 Experiences of Health Services and Suggested Improvements	94
3.5 Summary	96
Chapter 4: Questionnaires	98
4.1 Introduction.....	98
4.2 Questionnaire methodology	98

4.2.1 Initial Questionnaire Development.....	98
4.2.2 Focus Group Consultation	99
4.2.2.1 Focus Group Feedback Summary – Mild Cognitive Impairment Group.....	101
4.2.2.2 Focus Group Feedback Summary - Advocates	102
4.2.3 Final Revisions to Questionnaires	103
4.2.4 Questionnaire Administration.....	103
4.2.5 Analysis of Questionnaire Data	105
4.2.5.1 Data entry.....	105
4.2.5.2 Statistical Analysis of Quality of Life Data	106
4.2.5.3 Statistical Analysis of the Healthcare Experiences Survey Data.....	106
4.2.6 Discussion of Methods Used	108
4.2.6.1 Questionnaire Development.....	108
4.2.6.2 Questionnaire Administration	110
4.2.6.3 Questionnaire Analysis	111
4.3 Questionnaire Results	114
4.3.1 Outcome Measure Results	114
4.3.1.1 People With Mild Cognitive Impairment: The Mild Cognitive Impairment Questionnaire (MCQ)	114
4.3.1.2 Advocates: The Mild Cognitive Impairment Questionnaire for Carers (MCQ- Carer)	118
4.3.2 Experiences of Healthcare Survey Results	123
4.3.2.1 Patient Survey	124
4.3.2.2 Advocate Survey	130
4.4 Discussion of Questionnaire Results.....	136
4.4.1 General	136
4.4.2 Patient Reported Outcome Measures	137
4.4.2.1 Discussion of Statistical and Technical Aspects	137
4.4.2.2 Discussion of Final Versions of the MCQ and MCQ-Carer	138
4.4.2.3 Interpreting the Scores of the MCQ and MCQ-Carer	139
4.4.3 Healthcare Experiences Survey	140

4.4.3.1 Discussion of Statistical and Technical Aspects	140
4.4.3.2 Discussion of Results of Healthcare Experiences Survey.....	140
4.5 Summary	149
Chapter 5 – Conclusion	151
5.1 Summary of Findings	151
5.2 Potential Avenues for Future Work	153
5.2.1 Further Development of the MCQ and MCQ-Carer	153
5.2.2 Guidance for Memory Services	153
5.3 Conclusion.....	154
Bibliography	156
Appendices.....	165
Appendix 1 – Interview Topic Guides	165
Interview Topic Guide for People With Mild Cognitive Impairment	165
Interview Topic Guide for Advocates	167
Appendix 2 – Examples of Study Literature from Interview Stage	168
Initial Information Sheet – Person With Mild Cognitive Impairment - Interview	168
Full Information Sheet – Person With Mild Cognitive Impairment - Interview	172
Full Information Sheet – Advocate - Interview	182
Consent Form – Person With Mild Cognitive Impairment– Interview.....	191
Consent Form – Advocate – Interview.....	193
Appendix 3 – Details of Revisions to Questionnaires Following Focus Group Feedback.....	195
Modifications to Questionnaires for the Mild Cognitive Impairment Group	195
Modifications to Advocate Questionnaires.....	198
Appendix 4 – Final Versions of Questionnaires	201
Questionnaire for People With Mild Cognitive Impairment	201
Questionnaire for Advocates	210
Appendix 5 – Medical Outcomes Study Short Form Health Survey, 12 item version (version 2) Population Norms (Median).....	220
Appendix 6 – Final Version of the Mild Cognitive Impairment Questionnaire (MCQ)...	221

Appendix 7 – Final Version of the Mild Cognitive Impairment Questionnaire for Carers (MCQ-Carer)	223
Appendix 8 – Coefficients Generated by Regression Analyses of the Healthcare Experiences Survey Data.....	225
Relationship Between Opinions About Improvements to Services and Mental Health	225
Relationship Between Opinions About Improvements to Services and Quality of Life	226
Relationship Between Healthcare Experiences Summary Score and Experiences of Individual Aspects of Memory Clinic	228

List of Tables

Table 1. Questionnaire focus group participant demographics.....	100
Table 2. Demographic details of questionnaire subjects with mild cognitive impairment	114
Table 3. Rotated component matrix resulting from factor analysis of questionnaire quality of life data for subjects with mild cognitive impairment	116
Table 4. Correlation of MCQ items to total correlations and internal reliability of domains	117
Table 5. Descriptive statistics for the dimensions of the MCQ from results of the survey.	118
Table 6. Demographic details of the advocate questionnaire subjects.....	119
Table 7. Rotated component matrix resulting from factor analysis of questionnaire quality of life data for advocates.....	121
Table 8. Correlation of MCQ-Carer items to total correlations and internal reliability of domains	123
Table 9. Descriptive statistics for the dimensions of the MCQ-Carer.....	123
Table 10. Percentage of people with mild cognitive impairment reporting a problem with aspects of general practitioner care in the ‘healthcare experiences survey’	125
Table 11. Percentage of people with mild cognitive impairment reporting a problem with aspects of memory clinic care in the healthcare experiences survey	126
Table 12. Percentage of people with mild cognitive impairment endorsing suggested improvements to services in the healthcare experiences survey.....	128
Table 13. Percentage of advocates reporting a problem with aspects of care at the general practitioner in the healthcare experience survey	131
Table 14. Percentage of advocates reporting a problem with aspects of memory clinic care in the healthcare experiences survey	132
Table 15. Percentage of advocates endorsing suggested improvements to services in the healthcare experiences survey	134
Table 16. SF-12v2 norms (median) for the 1998 U.S. Population, Standard (4-Week) Form	220

Table of Abbreviations

Abbreviation	Full Term
AA	Alzheimer's Association
AAPA	American Academy of Physicians' Assistants
AD	Alzheimer's disease
ADL	Activity of daily living
ADNI	Alzheimer's Disease Neuroimaging Initiative
ALSAQ-40	40 item Amyotrophic Lateral Sclerosis Assessment Questionnaire
aMCI	Amnesic mild cognitive impairment
CDR	Clinical dementia rating
CMHT	Community mental health team
CQUIN	Commissioning for Quality and Innovation
DEEPARC	Dementia Electronic Prescribing and Research Contact System
DEMA	Daily Enhancement of Meaningful Activity programme
DeNDRoN	Dementia and Neurodegenerative Diseases Research Network
DoH	Department of Health (UK)
DQOL	The Dementia Quality of Life Instrument
EHP-30	Endometriosis Health Profile-30
EMA	European Medicines Agency
FDA	Food and Drug Administration (USA)
GP	General Practitioner
HADS	Hospital Anxiety and Depression Scale
HRQL	Health related quality of life
IADL	Instrumental activity of daily living
ICD-10	International Statistical Classification of Diseases and Related Health Problems, 10th Revision
MCI	Mild cognitive impairment
MCQ	Mild Cognitive impairment Questionnaire (for PWMCI)
MCQ-Carer	Mild Cognitive impairment Questionnaire (for carers)
MCS	The Medical Outcomes Study short form health survey (version 2) mental health component score
MMSE	Mini-Mental State Examination score

Abbreviation	Full Term
MRC	Medical Research Council
N	Number
NDS	National Dementia Strategy
NIA	National Institute on Aging
NICE	National Institute for Clinical Excellence
NIHR	National Institute for Health Research
NPI	Neuropsychiatric inventory
NPS	Neuropsychiatric symptoms
NRES	National Research Ethics Service
OPTIMA	Oxford Project to Investigate Memory and Ageing
PCS	The Medical Outcomes Study short form health survey (version 2) physical health component score
PIS	Patient information sheet
PPE-15	Pickler Patient Experience Questionnaire (short form version)
PROCOG	Patient Reported Outcomes in Cognitive Impairment tool
PROM	Patient reported outcome measure
PWMCI	Person / people with mild cognitive impairment
QoL	Quality of life
QoL-AD	Quality of Life Alzheimer's Disease Scale
R&D	Research and development
REC	Research ethics committee
SCI	Subjective cognitive impairment
SD	Standard deviation
SF-12	The Medical Outcomes Study short form health survey (12 item version)
SF-36	The Medical Outcomes Study short form health survey (36 item version)
SMC	Subjective memory complaint

A Note on Terminology

The term 'person with mild cognitive impairment' (PWMCI), rather than patient, has been used in this thesis as many PWMCI are not patients i.e. are not engaged with healthcare services. An exception to this is in cases where the PWMCI is being discussed specifically as a user of healthcare services.

The term 'advocate' has been used in this study to denote a relative or friend that the PWMCI felt had been affected by their cognitive problems. This term was used in preference to 'carer' or 'care-giver' as, by definition, most people with MCI do not have significant difficulty with standard ADLs and therefore do not require 'care' in the usual sense of the word. However, in the introduction (Chapter 1) and literature review (Chapter 2) the term 'carer' or 'caregiver' was used throughout to reflect the terminology used in the literature cited. In the interests of clarity, in the literature given to participants in the study the term 'relative or friend' was used rather than advocate. The patient reported outcome measure (PROM) developed for use with advocates of people with MCI was named the MCQ-Carer so that population in whom the measure is intended for use is unambiguous.

Chapter 1: Introduction

1.1 Thesis Structure

Mild cognitive impairment (MCI) is a state between normal cognition and dementia; it is common and associated with an increased risk of dementia. It is increasingly recognised that people with MCI (PWMCI) and their caregivers experience a range of practical and emotional difficulties which health and social care services often fail to address adequately, although evidence regarding many aspects of this topic is limited at best. Therefore the aim of this work was to gather detailed information about the experiences of PWMCI and their caregivers, with particular reference to their involvement with healthcare services, to use this information to develop a patient reported outcome measure (PROM) and equivalent measure for caregivers and to suggest potential improvements to services. The PROM for the PWMCI is to be designated the Mild Cognitive impairment Questionnaire (MCQ) and that for caregivers as the MCQ-carer.

In Chapter 2 the current literature regarding patient and caregiver experience in MCI is reviewed, with particular emphasis on experiences of healthcare and existing measures of outcome in these groups.

In the first stage of the study in-depth, semi-structured interviews with PWMCI and their caregivers were conducted in order to gain a detailed picture of the experiences of these groups – both in everyday life and in their contact with healthcare services. In the first part of Chapter 3 the methodology for conducting the interviews and analysing the resulting data is described, including a discussion of the justification for, and limitations of, this methodology. In the second and third part of this chapter respectively the results of the interviews are described and discussed (with reference to the existing literature).

In the second stage of the study the results of the interviews were used to generate items for initial versions of the outcome measures for PWMCI and caregivers and to design surveys of experiences of healthcare for the two groups. The initial outcome measures and surveys were incorporated into two questionnaires (one for patients and one for caregivers); these were refined after review by a focus group and then administered to PWMCI and their caregivers by post. In the first part of Chapter 4 the methods used to develop the outcome measures and surveys and to administer the questionnaires are described. In the second part of the chapter the results of administration of the initial versions of the outcome measures and the surveys are presented and analysed. In the final part of this chapter the results of the analysis of the initial versions of the outcome measures are discussed and final versions (the MCQ and MCQ-Carer) are presented; the results of the patient and caregiver

surveys are also discussed and some potential improvements to healthcare services suggested.

In Chapter 5 the overall results of the study and their implications are briefly discussed together with potential avenues for further work.

1.2 Background

1.2.1 Introduction to Mild Cognitive Impairment

The defining criteria for MCI most commonly used in research are those first proposed by Petersen *et al.* in 1999 (Petersen et al., 1999) i.e. for a diagnosis of MCI there should be: memory complaint from the patient (preferably corroborated by an informant), evidence of objective memory impairment (for age and education) on testing but preserved general cognitive function, intact activities of daily living (ADLs) and an absence of dementia. In 2011, a working group from the National Institute on Aging and the Alzheimer's Association published revised 'core clinical' criteria for the diagnosis of 'MCI due to Alzheimer's disease (AD)'; these altered Petersen's original criteria to include cognitive changes in domains other than memory, to emphasise the importance of a *decline* in cognitive abilities and to specify that, although independence in functional abilities should be preserved, complex ADLs may be affected (Albert et al., 2011). The revised criteria state that MCI may be diagnosed if there is: evidence of concern (from the patient, an informant or a clinician) about a change in cognition, impairment in one or more cognitive domain(s) on examination (greater than expected for age and education), preservation of independence in functional activities (with minimal aid or assistance) and an absence of dementia. The working group also published 'research criteria' which included the use of biomarkers (such as markers of amyloid beta deposition) to establish the likelihood that MCI is due to a symptomatic, pre-dementia phase of AD. MCI can be divided into four subtypes depending on which cognitive domains are affected (Petersen et al., 2009): amnesic single domain (in which there is impairment of memory only), amnesic multiple domain (in which there is impairment of memory and (an)other cognitive domain(s)), non-amnesic single domain (in which there is impairment of a single, non-memory cognitive domain) and non-amnesic multiple domain (in which there is impairment of multiple, non-memory cognitive domains).

The reported prevalence of MCI varies depending on the definition used and population studied. Prevalence in general older populations where strict research definitions (such as the Petersen criteria given above) are used seems to be approximately 3% (Gauthier et al., 2006, Anstey et al., 2008, Palmer et al., 2008, Wright, 2009). Where more inclusive definitions are used (such as "cognitive impairment, no dementia") prevalence estimates

may be as high as 25%. Similarly, the incidence of MCI quoted in the literature is dependent on the definition used and ranges from 1 to 5% per year (Gauthier et al., 2006, Chertkow et al., 2008). Current estimates are that approximately 1.5 million people in the UK have MCI (Smith et al., 2010).

The majority of interest in MCI has been as a result of the associated increased risk of dementia. Like prevalence, the quoted conversion rate from MCI to dementia is dependent on the definitions used and the populations studied (Ganguli et al., 2011). Annual incidence of dementia is around 3% in those with MCI in the general population (Farias et al., 2009, Mitchell and Shiri-Feshki, 2009, Ganguli et al., 2011) compared to approximately 0.5% in all people over 60 in the UK (National Institute for Clinical Excellence and Social Care Institute for Excellence (England and Wales), 2006). In clinic based research populations the rate of progression from MCI to dementia is higher than in community based populations: estimates for clinic based population vary widely and have been quoted as anything between 10 and 41% per year, although most studies suggest a figure of between 10 and 15% (Gauthier et al., 2006, Chertkow et al., 2008, Farias et al., 2009, Mitchell and Shiri-Feshki, 2009, Adams, 2006). It is commonly reported that subjects with amnesic MCI (aMCI) have a higher rate of conversion to AD than those with other subtypes who more frequently progress to other disorders such as vascular dementia (Petersen et al., 2001a). It is also known that a significant proportion of people meeting criteria for MCI show at least some improvement in cognition over time; studies have shown this to be in the case in 11 – 44% of those diagnosed with MCI at baseline (Wright, 2009, Gauthier et al., 2006, Wahlund et al., 2003, Matthews et al., 2008).

1.2.2 Relevant Policies

It is likely that the rate of diagnosis of MCI will increase in the UK over the coming years due both to the ageing population and to various government and health service strategies relating to the early diagnosis of dementia which will probably have the secondary effect of increasing the rate of diagnosis of MCI:

The National Institute for Clinical Excellence (NICE) guideline on dementia published in 2006 (National Institute for Clinical Excellence and Social Care Institute for Excellence (England and Wales), 2006) states that *‘primary healthcare staff should consider referring people who show signs of MCI for assessment by memory assessment services’*.

The National Dementia Strategy (NDS) published by the UK Department of Health (DoH) in 2009 sets out 17 key objectives to improve the quality of services for people with dementia, focussing on improved awareness, earlier diagnosis and intervention and a higher quality of

care (Department of Health, 2009b). The strategy is being coordinated nationally with implementation beginning at a local level over the five years from 2009 onwards. MCI is not specifically mentioned in the strategy, however some of the objectives are likely to have an effect on the rate of diagnosis of MCI as consultation and referral rates to secondary care increase amongst patients with memory problems. Objectives which are particularly relevant include: Objective 1: 'improving public and professional awareness and understanding of dementia' and Objective 2: 'good quality early diagnosis and intervention for all'. In September 2010 the DoH decided to focus on five main priorities – one of which was early diagnosis and intervention in primary care (Department of Health, 2010). To complement the NDS the DoH national campaign to raise public awareness of the early features of dementia was launched in November 2011 (Department of Health (England), 2011). This incorporated a media campaign to raise public awareness of the fact that many cases of dementia go undiagnosed. The campaign was particularly aimed at the friends and family of those at risk of dementia and emphasised the importance of consulting a health professional for assessment where they had concerns about a person's memory. There is some evidence that referrals to memory clinics from primary care has increased since the NDS was published (Menon and Lerner, 2011).

In April 2012 the British Prime Minister, David Cameron, launched his 'dementia challenge' which '*aims to deliver major improvements in dementia care and research by 2015*' and '*build on the achievements of the NDS*' (Department of Health, 2012). This DoH guidance set out a number of commitments relating to improving awareness, quality of care and research in dementia; these included two which are particularly likely to increase the rate of MCI diagnosis as a by-product of cognitive screening programs: The first of these was the commitment to increase diagnosis rates through regular checks for over-65s: General Practitioners (GPs) and other health professionals are to make patients aged 65 and older aware of memory clinics and refer those in need of assessment; this commitment includes targets for rates of diagnosis. The second important pledge was the commitment to financial rewards for hospitals offering quality dementia care: From April 2012, £54m has been made available through the Dementia Commissioning for Quality and Innovation (CQUIN) to hospitals offering dementia risk assessments to all over-75s admitted to their care.

Other bodies aside from the DoH encourage early diagnosis in dementia, for example The World Alzheimer Report 2011 emphasised the importance of early diagnosis and intervention – both on an individual level for patients and carers and in terms of financial

benefits for society (Alzheimer's Disease International, 2011). The meaning of 'early diagnosis' was discussed, acknowledging that for some, this means 'timely diagnosis', at the point at which the individual or carer first become concerned rather than screening the general population to detect disease early. Clearly 'timely diagnosis' in this context can apply to individuals with MCI as well as those with dementia.

Several recent reports have highlighted the need for more research in this field: The Medical Research Council (MRC) and DoH convened a Ministerial Summit on Dementia Research in 2009, the independent report of which stated: *'There is a need for more clinical studies of people with mild cognitive impairment'* (Department of Health and Medical Research Council, 2009). Both the National Institute for Health Research (NIHR), in their 2011 call for research, and the Prime Minister's Challenge mentioned above (Department of Health, 2012), emphasized the importance of research into the social impact of living with cognitive impairment.

1.2.3 Current Support and Information for People Affected by Mild Cognitive Impairment

As discussed in the review of current literature in Chapter 2, there is relatively little published evidence about the experience of living with MCI or caring for people with the condition. The work which has been done is observational in nature and there are few interventional studies to provide evidence about the most effective way to support these groups; this is in contrast to dementia where there is quite a large body of evidence on these topics.

Overall, the evidence which does exist suggests that both PWMCI and their advocates experience more difficulties than might be expected when considering Petersen's research definition of MCI which states that, despite a degree of cognitive impairment, these individuals have intact general cognition and are able to function independently in terms of ADLs (Petersen et al., 2001b). The evidence also suggests that PWMCI are a heterogeneous group with regards to their experiences and support needs which further underlines the need to develop standardised assessment tools for this group.

In keeping with the paucity of published evidence on the topic, and in stark contrast to dementia, there are few national or international guidelines regarding the management of MCI (Palmer et al., 2010). The only published guidelines which specifically relate to the management of MCI were published in North America: The American Academy of Neurology's 'practice parameter' (Petersen et al., 2001b) and The American Academy for Physicians' Assistants (AAPA) guidelines on the management of dementia and MCI (Boissonneault, 2010). These documents make recommendations about the management

options for MCI, including, in the AAPA's guidance, that '*clinicians should consider the social and familial impact of MCI*'. In the UK, the NICE guidance on dementia (National Institute for Clinical Excellence and Social Care Institute for Excellence (England and Wales), 2006) states that '*memory assessment services that identify people with MCI ... should offer follow-up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage*'.

1.2.4 Patient Reported Outcome Measures in Mild Cognitive Impairment

As discussed in the literature review in Chapter 2, and confirmed by published reviews of the topic (Weiner et al., 2012, Frank et al., 2011), there are very few assessment tools designed specifically for use in MCI – either for cognitive or comprehensive needs assessment.

One of the objectives of this project is to develop a patient reported outcome measure (PROM) and equivalent measure for advocates in MCI (which, for the sake of simplicity, will also be referred to as a PROM in this document). PROMs are defined by the UK Department of Health as '*measures of a patient's health status or health-related quality of life. They are typically short, self-completed questionnaires, which measure the patients' health status or health related quality of life at a single point in time*'. They are being used with increasing frequency - to provide information on the impact of disease in clinical practice and to measure outcomes both in clinical practice and clinical trials (Revicki, 2002, Leidy et al., 1999). Their increasing popularity is reflected by the fact that the UK Department of Health made it mandatory for PROMs data to be collected for all patients undergoing hip or knee replacement, varicose vein or groin hernia repair surgery within the NHS from 2009 (Department of Health, 2009a). The European Medicines Agency (EMA) issued guidance for industry regarding the use of PROMs in medical product development in 2005 (European Medicines Agency, 2005) as did the US Food and Drug Administration (FDA) in 2009 (US Department of Health and Human Services et al., 2009). The importance of measuring health related quality of life (HRQL) as an outcome measure in clinical trials in cognitive impairment has been commented on by several authors (Winblad et al., 2001, Rockwood et al., 2006).

A PROM for carers specific to MCI is also likely to be a useful tool; many carers of PWMCI have already taken on caring responsibilities but these are likely to be different from those involved in caring for someone with physical health problems or dementia (Gallagher et al., 2011) – therefore existing measures developed for these groups of carers may well not be applicable to those of PWMCI. In addition, some of the studies described in Chapter 2 found

that carers' *subjective* assessments of factors such as burden or severity of the PWMCI's cognitive impairment were correlated with adverse effects (such as decreased marital quality) whereas *objective* measures of the same factors were not (Garand et al., 2007, Bruce et al., 2008). This suggests that a PROM may be a more accurate reflection of true carer experience than existing, objective measures.

The review of the literature identified only one PROM developed for use in MCI and this was, in fact, developed based on interviews with both PWMCI and AD and has only been validated for use in North America (Frank et al., 2006a). No PROMs designed for use in carers of PWMCI were identified. Discussing the lack of MCI-specific HRQL scales in their review of PROMs for MCI, Frank et al stated:

'...the value of disease-specific HRQL assessment for treatment evaluation in MCI and prodromal AD is limited by lack of consensus on domains to include and lack of clarity about how to weight domains for scoring. The HRQL impact of MCI, as distinct from that of later disease, remains to be defined'.

They concluded:

'...the time is right for development of new patient-reported measures for MCI. Although measurement from the perspective of patients with MCI and prodromal AD is still at an early stage, the development of new measures...should be pursued to increase the tools available to expand our understanding of mild levels of cognitive impairment'.

Consequently, this thesis aims to develop such measures for PWMCI and carers. In the next chapter a review of the relevant published literature will be set out; in subsequent chapters the development of the measures will be described and then discussed in the context of this literature.

Chapter 2: A Critical Review of The Literature

The concept of mild cognitive impairment (MCI), as it is recognised today, was first 'formalised' when Petersen published his definition in 1999 (Petersen et al., 1999). Most of the literature relevant to this work has therefore been published since this time, with an exponentially increasing volume of publications between the late 1990s and the current time, for example 20 articles with the phrase 'mild cognitive impairment' in the title were published in 1999 compared to 633 in 2011. Consequently, there is a large volume of published literature on the subject of MCI and a careful literature search, as described below, was carried out in order to identify those articles relevant to this work i.e. those relating to: the experiences living with MCI for those with the condition and their carers (with particular reference to healthcare), potentially helpful interventions for these groups and the tools available to measure patient (and carer) experience and the outcomes of interventions.

2.1 Methods

The Embase, Medline and PsychINFO databases were searched via the NHS Evidence Health Information Resources website (formerly the National Electronic Library for Health) in August 2010, the search was repeated at regular intervals during the course of the research up to October 2012. The titles of all papers to October 2012 were searched for the following keywords (without explosion):

- 'mild cognitive impairment' OR MCI, combined in turn (using AND) with:
 - symptoms (limited to papers from 2008 – current)
 - 'subjective complaint'
 - care*
 - experience*
 - clinic* (limited to papers from 2008 – current)
 - 'primary health care' OR 'general pract*' OR GP
 - consult* OR attend* OR 'seeking help' OR 'help seeking'
 - 'patient perception'
 - future

- 'memory clinic*' combined in turn (using AND) with:
 - experience*
 - perception*

- 'cognitive impairment' OR MCI OR dementia combined in turn (using AND) with:
 - 'patient reported outcome*'
 - 'outcome measure*'
 - PRO OR PROs
 - PROM or PROMs
 - 'care* outcome*'

No limits were applied except as specified in the list above. In addition, a search of the Cochrane Library was performed using the 'advanced search' facility to search 'the title, abstract and keywords of articles using the terms 'Mild Cognitive Impairment' and 'MCI' - Cochrane and 'other' reviews were considered. The 'Topics' section on the NHS Evidence website was searched for the term 'mild cognitive impairment', the results were filtered by 'type of information' and articles in the sections 'Guidelines', 'Patient Information', 'Policy and Service Development' and 'Quality Measures' were reviewed.

The titles and abstracts of the papers identified using this strategy were screened for relevance using the following criteria: Papers were included in the review if they were primarily concerned with aspects of MCI relating to everyday experiences of patients or carers, their experiences of health or social care or outcome measures for use in these groups. Articles published in languages other than English were excluded. Abstracts were included if they contained sufficient information, unpublished studies were not.

Citations were excluded from the review if, on examination of the title and / or abstract, they were clearly not relevant to the topic being reviewed. The full text versions of papers which appeared to be relevant following initial screening were obtained and reviewed further.

The search strategy yielded 1020 articles, 243 of which were duplicates. After review of the title and / or abstract of the 777 unique articles, the full versions of 105 papers were obtained and reviewed. 56 of these papers obtained met the inclusion criteria. The reference lists of all relevant articles were examined for any additional articles of interest, this yielded 6 further articles, therefore in total 62 articles were included in this review.

2.2 Patients' Experience of Mild Cognitive Impairment

2.2.1 General Experiences of Living with Mild Cognitive Impairment

2.2.1.1 Cognitive Changes

Given the definition of MCI, which mandates cognitive complaints from the person with MCI (PWMCI) or informant, it is to be expected that people living with MCI should report noticing cognitive changes in various domains – and this is indeed the case. Qualitative studies have provided useful in-depth information about the experiences of people living with MCI, including their perceptions of cognitive changes: Guided interviews of eight very recently diagnosed patients in Holland identified four common themes (Joosten-Weyn Banningh et al., 2008) one of which was 'changes noticed by the patient' – these were often cognitive in nature, for example 'forgetfulness' and 'poor concentration'. Frank *et al.* carried out focus group interviews of 20 people with MCI and 11 'informants', as well as similar numbers of people with mild probable AD (Alzheimer's disease) (Frank et al., 2006b). They also found that PWMCI commonly reported cognitive changes affecting recall, verbal fluency and processing skills. As linked PWMCI and informants were interviewed in this study in many cases it was possible to compare their reported experiences.

Lu *et al.* carried out open ended interviews with eleven PWMCI in order to identify '*commonalities of the lived experience of being diagnosed and living with MCI*' (Lu et al., 2007a). They described a longitudinal 'journey' experienced by PWMCI beginning with the gradual awareness of their problems, followed by efforts to maintain a sense of 'being able' and finally development of strategies to maintain 'a sense of self'. The first of these elements incorporated an awareness of worsening memory. Although this study provided detailed information about people's current experiences of living with MCI the mean time from diagnosis to interview was 2.5 years which may have limited subject recall of issues which were particularly relevant at the time of diagnosis.

In a study in which questionnaires about health, beliefs about their diagnosis and coping were administered to 63 PWMCI the symptoms endorsed by more than half of the respondents were cognitive in nature (Lin and Heidrich, 2012).

2.2.1.2 Function

Despite the stipulation in the original Petersen definition of MCI that basic activities of daily living (ADLs) should be intact it has been increasingly recognized that more complex (or 'instrumental') ADLs (IADLs), such as managing medications or finances, may be affected

by MCI and, in fact, it is this 'minimal impairment' which helps differentiate MCI from normal aging (Winblad et al., 2004).

Difficulties with IADLs in MCI have been identified in quite a number of studies, often at a rate between those experienced by people with dementia and normal controls: In a questionnaire based study of 46 people recently diagnosed with MCI subjects reported a need for assistance with complex ADLs, although to a lesser degree than the levels of assistance that their carers reported they required (McIlvane et al., 2008). In a large study based on data from the Alzheimer's Disease Neuroimaging Initiative (ADNI) informant reports of function (as measured with the quantitative Pfeffer Functional Activities Questionnaire) for nearly 400 PWMCI were compared with those for controls and subjects with mild AD (Brown et al., 2011). The authors found that functional impairment in one or more of the domains covered by the questionnaire was present in 72% of the PWMCI compared to 8% controls and 95% subjects with mild AD and that, perhaps unsurprisingly, greater functional impairment was associated with poorer performance on various neuropsychological tests. A prospective case control study of 107 PWMCI also showed that they were more likely to report deficits in complex functions, such as managing finances and preparing food, than were cognitively normal controls (Tabert et al., 2002). The authors found that a subset of people *overestimated* their functional abilities when compared with informant reports (indicating either a diminished awareness of their functional limitations or an underestimation of their abilities by the informant) and that this subset had a greater risk of developing Alzheimer's disease. A case control study in Korea also found that PWMCI had significantly more difficulty with IADLs than did controls (Ahn et al., 2009); IADLs where significant differences in ability were identified included telephone use, meal preparation, management of medication, participation in leisure activities and keeping of appointments. In this study PWMCI's ability to perform IADLs was assessed from caregiver reports therefore the results were unaffected by any decreased insight on the part of the PWMCI. A study of functional ability in approximately 300 French people with cognitive impairment insufficient to meet the criteria for dementia also found rates of difficulty with various ADLs to be significantly greater than in cognitively intact subjects in the same age group (30.8% vs. 3.3%) (Artero et al., 2001). Interestingly, some of the ADLs with which subjects in this study most commonly reported difficulty (e.g. independent toileting, mobility and bathing) were much more basic than the IADLs in the studies described above. The subjects included in this study underwent extensive neuropsychiatric, clinical and imaging investigations; the criteria used to diagnose MCI were: having subjective cognitive complaint plus a reported a cognitive change over the preceding year plus having cognitive scores greater than one standard deviation below the mean expected score for age and education but who not

meeting the criteria for dementia. However, by the Petersen criteria, those subjects with limitations of basic ADLs, cannot be diagnosed with MCI which means that the results of this study should be interpreted with caution.

One recent study specifically examined social function in PWMCI and mild dementia (Henry et al., 2012): it concluded that there was no difference in informant ratings of socially insensitive behaviour between the control and MCI groups (whereas the group with mild dementia was rated as displaying elevated levels of such behaviour). However, this study used the quantitative 'Peer-Report Social Functioning Scale' which may be less sensitive in detecting subtle effects on social function than qualitative methods, such as those used in de Vriendt's study of PWMCI (described in detail below) which did detect effects on subjects' ability to socialize (De Vriendt et al., 2012).

There is some evidence that PWMCI may not always spontaneously report problems with function, even where they are present: A qualitative study involving interviews with 37 patients newly diagnosed with aMCI and 22 informants found that, although participants did not explicitly report functional problems resulting from cognitive problems, descriptions of their typical day-to-day activities did reveal subtle difficulties with advanced ADLs such as the use of electronic equipment, cooking complex meals, complex economic activities and socializing (De Vriendt et al., 2012) It is also likely that the problems with function experienced depend on MCI subtype: In a study of nearly 500 subjects with MCI carried out in California functional deficits were found to vary by MCI subtype – those with aMCI were more likely to have difficulty with recall (e.g. for names) and less likely to have difficulty with basic ADLs (such as eating and continence) than those with non-amnesic MCI (Weston et al., 2011)

2.2.1.3 Emotional Consequences and Neuropsychiatric Symptoms

Neuropsychiatric symptoms (NPS) are known to be a common feature of MCI: In a population based cohort study of PWMCI, carried out as part of the Cardiovascular Health Study in the United States, Neuropsychiatric Inventory (NPI) scores were examined for 320 people classified as having MCI. 43% were found to have had at least one NPS in the preceding month with the commonest symptoms being of depression (20%), apathy (15%) and irritability (15%) (Lyketsos et al., 2002) This has subsequently been confirmed in another quantitative study where similar rates of NPS were identified (Feldman et al., 2004). However, there has been some disagreement as to the psychological impact of living with MCI, for example the questionnaire based study of recently diagnosed patients found measures of psychological wellbeing (such as depression and life satisfaction) to be within normal limits (McIlvane et al., 2008).

Results of some of the qualitative studies, however, appear to confirm that negative emotional reactions are common in PWMCI. For example, one of the major themes identified in Joosten-Weyn's interview based study was 'consequences' which were commonly negative emotions experienced by PWMCI regarding their cognitive problems (Joosten-Weyn Banningh et al., 2008). The subjects in Lu *et al.*'s study also described a range of negative emotional reactions to their memory problems (Lu et al., 2007a). Frank *et al.*'s study identified a theme of embarrassment / shame about their problems resulting in a tendency to attempt to conceal them (to a greater extent than the patients with mild AD included in the study did) (Frank et al., 2006b). DeVriendt *et al.*, in their study of function in MCI, also commented that the combination of impaired function and impaired coping they identified led, in many cases, to negative emotional consequences (De Vriendt et al., 2012). In a study involving semi-structured interviews with 25 people diagnosed with MCI at specialist memory clinics 'fear and uncertainty' were found to be a major theme (Roberts and Clare, 2012).

Lin and Heidrich, in their questionnaire based study, found that PWMCI within their study population described a diverse range of emotional responses and often disagreed with one another about the consequences, for example 46% participants agreed with the statement 'MCI makes me feel uncertain about the future', while 38% disagreed (Lin and Heidrich, 2012). This is in keeping with the fact that PWMCI are a heterogeneous group who are likely to differ widely in their responses to the diagnosis.

2.2.1.4 Coping

The coping mechanisms employed by PWMCI have also been examined in several studies. One of the themes identified in Joosten-Weyn's study was 'coping' and they identified three types of coping mechanism in their subjects:

- Emotion orientated e.g. resignation
- Problem solving orientated e.g. developing strategies to aid memory
- Avoidance orientated e.g. disguising their memory difficulties (Joosten-Weyn Banningh et al., 2008)

Beard and Neary also identified use of the first two of these strategies in the PWMCI interviewed for their study (Beard and Neary, 2012) as did Lin and Heidrich in their questionnaire based study (Lin and Heidrich, 2012). In a qualitative study of 'self-initiated health behaviours' following a diagnosis of MCI, 53 people were interviewed about changes they had made as a result of their diagnosis. 'Symptom driven' changes, such as the use of compensatory strategies or cognitive exercises, were reported most commonly and the

authors comment that these strategies broadly equate to the 'problem focused' coping strategies described above (Morgan et al., 2012).

The final theme identified in Lu *et al.*'s qualitative study concerned coping mechanisms – some similar to those described above (e.g. acceptance and strategies to aid memory) and some not identified in Joosten-Weyn's study (for example information seeking, careful communication in order to maintain relationships and efforts to maintain hope) (Lu et al., 2007a).

A study of 56 'triads' consisting of an 'elder' with MCI plus a primary and a secondary 'care partner' used semi-structured interviews to assess the subjects' perceptions of MCI and their associated coping mechanisms. The authors concluded that coping style appeared to differ with the degree of acknowledgement of problems: subjects who displayed 'passive' acknowledgement (where memory problems were acknowledged but attributed to causes other than MCI) tended to rely on others for assistance and those in other groups were more likely to seek active strategies such as using reminder lists (Roberto et al., 2011)

2.2.1.5 Attributions

The causes to which PWMCI attribute their symptoms have been discussed in several studies. Attributions vary widely but there are several which recur across the literature including: normal aging, physical health problems and personality. 'Normal aging' was by far the commonest attribution in that it was mentioned by PWMCI in almost every relevant study and, in addition, was often the most frequently described attribution within each study. For example, in one qualitative study 11 people who were aware of the term 'Mild Cognitive Impairment' relating to their cognitive problems were interviewed about their perceptions of their diagnosis (Lingler et al., 2006), they cited 'normal ageing' as the most common explanation for their symptoms. This was also the case in the study involving semi-structured interviews with 25 PWMCI, all of whom had had their diagnosis disclosed to them at the memory clinic (Roberts and Clare, 2012). Other qualitative and questionnaire based studies have had similar results (McIlvane et al., 2008, Lin and Heidrich, 2012, Beard and Neary, 2012).

One of the themes identified in Joosten-Weyn's study was 'Attributions' described by the PWMCI and these included normal ageing, personality, dementia and 'somatic' origins (Joosten-Weyn Banningh et al., 2008). In Lu *et al.*'s interview based study the theme of 'gradual awareness of problems' also incorporated a discussion of attributions. Many subjects in this study, in common with those in Joosten-Weyn's, attributed their symptoms to physical health problems including medication side effects. Others blamed an episode of

significant personal loss (such as bereavement) and, again, normal ageing (*Lu et al., 2007a*).

Beard and Neary noted that the people they interviewed were particularly keen to deny any association between their experiences and AD, stating that their awareness of their own limitations distinguished their condition from dementia (Beard and Neary, 2012). In contrast, Roberts and Clare found that concern about memory difficulties representing the beginnings of dementia was heightened by personal experience of others with dementia or by depictions in the media (Roberts and Clare, 2012).

In the qualitative study of the degree of 'acknowledgement' of memory impairment described above the authors categorised the degree of acknowledgement into (Roberto et al., 2011):

- 'Complete' – where all members of the triad fully acknowledged the PWMCI's limitations and attributed them to MCI
- 'Passive' – where memory problems were acknowledged but attributed to other causes, often physical health problems. PWMCI in this group often had reduced insight into their difficulties
- 'Partial' – where memory problems were acknowledged but 'personalised' i.e. attributed to something over which members of the triad had control – such as the degree of effort applied to remembering on the PWMCI's part or the way in which care partners interacted with them
- 'No acknowledgement' – where all members of the triad denied major memory problems.

Approximately one third of the triads fell into each of the first of these three categories with only 2 families in the 'no acknowledgement' group. The authors found that the degree of acknowledgement was influenced most strongly by families' prior experiences of other people with dementia: triads where a member had *professional* experience of dementia (e.g. was a healthcare worker) tended to have a higher degree of acknowledgement whereas those with prior *personal* experience (e.g. another family member with dementia) were under-represented in the 'complete acknowledgers' group, seemingly because they minimised the PWMCI's difficulties in comparison with that of the person they had known with dementia.

2.2.1.6 Insight and Mild Cognitive Impairment

The issue of whether PWMCI have reduced insight into their condition is key to the interpretation of the literature described here, for example the findings of studies where there were no informant reports may have been inaccurate if the PWMCI in these studies had

reduced insight. It is well recognised that impaired insight for deficits ('anosognosia') is a common feature of dementia (Starkstein et al., 1997), however the degree to which insight is impaired in MCI is more controversial.

Some studies in this area have concluded that PWMCI do under-report cognitive and functional limitations: A study in which individuals with aMCI were compared to those with mild AD and controls found that the subjects with aMCI and mild AD had a similar degree of impaired insight into their memory problems and that this was greater than in controls (Vogel et al., 2004). Frank *et al.* commented that the PWMCI in their qualitative study appeared to have reduced insight into their difficulties when compared to informant reports, although this was less marked than in their mild AD group (Frank et al., 2006b). In contrast, one study comparing self and informant reports of everyday functional abilities (where a discrepancy was taken to indicate decreased insight on the part of the PWMCI) found no difference in insight between controls and PWMCI (Farias et al., 2005).

The conflicting results described above may be, at least in part, due to the difficulties inherent in measuring insight in this group. A method commonly used is the comparison of the reports of informants and PWMCI – with a discrepancy taken to indicate decreased insight on the part of the PWMCI. As several authors have commented, where the informant is a caregiver the assumption that their reports are accurate may be erroneous as they may be influenced by a number of factors such as caregiver burden, neuropsychiatric symptoms or their own cognitive problems (Vogel et al., 2004, Frank et al., 2011). Indeed, in a study where assessment of the cognitive function of 119 PWMCI using standardised neuropsychological testing was compared to assessment using informant reports, it was found that there were significant differences in the prevalence of impairment in 7 of the 8 cognitive domains examined as rated by informants compared to formal testing (Abbate et al., 2011). It may also be that insight changes as MCI progresses (Lu et al., 2007a) or varies between subtypes of MCI: Tabert's longitudinal cohort study of just over 100 PWMCI found that, although there was no overall difference between self- and informant-reported ratings of IADLS between the MCI and control group, in the subgroup of PWMCI who under-reported functional deficits when compared with their informant's report there was an increased risk of conversion to AD (Tabert et al., 2002) – this may indicate that insight is reduced only where MCI represents a pre-AD stage of dementia.

In an effort to address some of the difficulties in measuring insight described above, Roberts and Clare used a qualitative approach (using interpretative phenomenological analysis) to gain a more in-depth understanding of 'meta-representational' awareness of symptoms and their impact in PWMCI (Roberts and Clare, 2012). They defined 'meta-representational

awareness' as the most complex expression of awareness - which '*encompasses aspects of self-identity and the environment*'. They concluded that all the PWMCI they interviewed did display awareness of their cognitive difficulties at this level but that various psychological and social factors influenced how this awareness was expressed. This finding was illustrated by the fact that, despite the conclusion that these subjects displayed awareness of their difficulties and the fact that they had been given the name of their diagnosis at their memory clinic appointment, none of them used the term 'MCI' during the semi-structured interviews.

Due to the poor comparability of studies in this area the authors of a systematic review of this topic were unable to draw any firmer conclusions than '*there is variability in awareness (of deficits) in PWMCI*' (Roberts et al., 2009). They mentioned many of the points made above as possible explanations for the conflicting results of the studies they reviewed and, in addition, pointed out that insight may vary depending on the domain to which it pertains (i.e. cognitive, behavioural or functional).

2.2.2 Patient's Experiences of Healthcare and Support Services

Diagnosis

Patient experience of diagnosis with MCI appears to vary widely. As part of the multi-centre European Descripa study 124 clinicians were surveyed about their practice of diagnostic disclosure in MCI. The results revealed that the diagnostic terms used to describe MCI were variable but that almost 80% of patients were given information about prognosis (Derksen et al., 2009). A survey of members of the American Academy of Neurology (most of whom reported assessing PWMCI at least monthly) revealed high rates of recognition of MCI as a clinical diagnostic term and of provision of information about physical and mental exercise to the patients they diagnosed. However, only 27% and 15% respectively reported providing information on support services or information in a written format (Roberts et al., 2010). A survey of over 1,200 UK psychiatrists with a special interest in older patients found that 91% reported making the diagnosis of MCI in clinical practice and that about two thirds felt that they were 'very' or 'extremely' familiar with the concept (Rodda et al., 2012). Some studies suggest a problem with recognition of MCI in primary care: A meta-analysis of studies (conducted in various countries) of GPs' ability to diagnose MCI found that only about 45% of cases of MCI (as defined by a validated cognitive severity scale) were recognised by GPs and that, where a diagnosis was made, it was recorded in the notes in only about 10% of cases (Mitchell et al., 2011).

Reasons for Presentation to Healthcare Services

Some work has been done on the reasons for presentation to health services among people with memory complaints. A study of nearly 300 non-demented subjects seeking assessment for memory problems in secondary care found that they reported higher total levels of subjective memory complaints (SMCs) than community based controls, particularly '*forgetting names of family members or friends*' (Pires et al., 2012). The authors did note, however, that the people seeking memory assessments had higher levels of depressive symptoms than the controls which may have been a confounder. Despite the findings of this study, which suggest (unsurprisingly) that memory concerns are the main driver for consultation, it is known that only a small proportion of those with SMC seek memory assessment (Waldorff et al., 2008). In a study of nearly 100 people with SMC (and Mini-Mental State Examination Scores (MMSEs) of 24 or greater) Hurt *et al.* aimed to establish which factors were associated with help seeking in this group; they identified social comparison (i.e. perceiving memory as being worse than others'), particular causal attributions (e.g. 'lack of blood supply to the brain') and having a close relative with dementia as being associated with seeking a memory assessment (Hurt et al., 2012). A study of 126 community dwelling people aged over 65 found that 31% reported significant SMC and that this group viewed their symptoms with comparable degrees of concern to other health problems such as hypertension (Begum et al., 2012). However only one participant with SMC had consulted their GP about their cognitive symptoms, a far lower proportion than those with physical health concerns (e.g. 80% of those with skin complaints had sought medical help despite the fact that this group displayed lower levels of concern about their symptoms than those with SMC). The authors commented that it was difficult to explain the low levels of help seeking in people with SMC, despite their relatively high levels of concern, based on their quantitative data.

Experiences at Memory Clinics

A number of authors have examined the experiences of patients and caregivers attending memory clinics – although these patients are heterogeneous in terms of eventual diagnosis and many of the studies have focused on patients receiving a diagnosis of dementia rather than MCI:

In a study of memory clinic users mixed methods were used to explore the experiences of 28 patients (most of whom received a diagnosis of dementia) and their caregivers on attending their first memory clinic assessment (Cahill et al., 2008). The authors found that the wait between referral to memory clinic and the appointment itself was often a distressing and unsettling time for patients and that, on arrival at the clinic appointment, over 50% of patients

reported feeling nervous about the forthcoming assessment. Patients in the study tended to have a general expectation of being provided with 'help' by the clinic. Immediately after the clinic appointment most patients reported feeling content with the assessment process – although a number did state that they found some aspects of it upsetting. They also reported feeling satisfied with the information they had been given, although many stated that they would have liked to have received information in written form in addition to verbally. In a study carried out in Holland, questionnaire based interviews of 31 patients attending memory clinics and 81 carers were used to assess satisfaction with five aspects of their experiences at the clinic (van Hout et al., 2001). Levels of satisfaction with communication of results, the usefulness of assessment and the clinician's attitude were generally high with 70-80% patients giving positive responses in these areas. However, patients reported being less satisfied with the clarity of information provided to them with only ~40% giving this a positive rating. Unfortunately, details of the diagnoses of patients included in this study were not reported.

A cross-sectional study of the participation preferences and decision-making capacity of 29 people with aMCI, which involved interviews with patients, relatives and referring physicians, was carried out in a German memory clinic (Hamann et al., 2011). Unfortunately the results for these patients were pooled with the 71 patients with mild AD also interviewed for the study and therefore results for the aMCI group alone were not available. In the combined group patients indicated a wish to be routinely involved in decision making, particularly that related to social decisions such as relocation to a nursing home, with their relatives playing a secondary role. Relatives' preferences, however, were that patients should have significantly lower participation than the patients stated they wanted, particularly in social decisions. The study included a quantitative assessment of decision making capacity which identified deficits in patients' capacity relating to 'understanding' – which the authors commented may '*restrict involvement of patients.....in social and medical decisions*'. By definition, people with aMCI should retain decision making capacity on these matters but unfortunately the data for decision making capacity scores for the aMCI group alone was not given in the paper therefore it is not possible to be certain whether the study's findings were driven by the patients with mild AD rather than MCI.

Only one of the qualitative studies of the experience of living with MCI included specific questions about subjects' experiences at memory clinic in their topic guide (Roberts and Clare, 2012). In this study PWMCI most commonly described their visit to the memory clinic as 'routine'; some subjects displayed confusion regarding the reason for referral to the clinic and some reported that they had received little information at the appointment.

Diagnosis Disclosure

Only one study of the effect of disclosing a diagnosis of MCI was identified in the literature review: Carpenter *et al.* evaluated symptoms of depression and anxiety in patients (and their advocates) before and after receiving a diagnosis of MCI (41 patients) or mild dementia (21 patients) in a research setting (Carpenter *et al.*, 2008). They found no clinically significant changes in these symptoms in either group following diagnosis. On a more general level, Beard's qualitative study identified themes of uncertainty and misinformation regarding the diagnosis and prognosis of MCI coupled with a dread of developing Alzheimer's disease (Beard and Neary, 2012). Clinicians may be reluctant to disclose a diagnosis of MCI for fear of causing the patient anxiety about the risk of dementia conferred by the diagnosis, particularly in light of the current lack of effective treatments for MCI. However, a study of the effect of disclosing AD risk based on ApoE genotype to family members of patients with AD identified no differences in NPS between individuals who were told their risk of AD and those who were not, even in those with genotypes associated with a greater risk of dementia (Green *et al.*, 2009). This suggests that informing patients that they have an increased risk of dementia does not necessarily increase levels of anxiety.

The general consensus in the current literature is that early diagnosis is important in dementia and some authors argue that those who undergo assessment and receive another diagnosis, such as MCI, may also benefit. As Alastair Burns, the national clinical director for dementia in the UK, wrote in a letter to the BMJ in 2012 (Burns, 2012):

'An early and timely diagnosis is important because it gives people a definitive answer to complaints that might be causing distress and anxiety (and reassures those who have memory problems but do not have dementia). This is what people with dementia want, and it means interventions can take place to avoid crises.'

The most common reaction to their diagnosis reported by patients in the studies reviewed was uncertainty – this was identified, for example, in Lingler's study of PWMCI's perceptions of their diagnosis (Lingler *et al.*, 2006), in Frank *et al.*'s study of the impact of living with MCI (Frank *et al.*, 2006b) and in Beard's study of PWMCI's opinions about their diagnosis (Beard and Neary, 2012).

Information Provision

There is currently a lack of educational and support materials aimed at specifically at PWMCI and their advocates (Austrom and Lu, 2009) making it difficult for clinicians to provide appropriate written information. Only three short fact sheets were identified, all entitled 'Mild Cognitive Impairment' published in The Neurologist in 2009 (Kernich, 2009), by

the Alzheimer's Society in 2005 (Alzheimer's Society, 2005) and in the Journal of the American Medical Association in 2009 (Torpy et al., 2008). Although the internet is an increasingly popular source of health-related information there are some limitations to its use in MCI: Given the increasing prevalence with age many PWMCI and advocates are in older age groups, these groups have been shown to be less likely to use the internet to search for information (Denizard-Thompson et al., 2011, Macfarlane et al., 2012). In addition, PWMCI's cognitive impairment may itself create a barrier to learning or retaining the skills required to use the internet effectively for this purpose.

2.2.3 Suggested Interventions and Support

The potential interventions for MCI which have received the most attention in the literature come under the umbrella of 'cognitive interventions', these are also known by other terms such as 'cognitive training', 'cognitive rehabilitation' and 'cognitive stimulation'. In their review of the subject Simon *et al.* define cognitive training as '*an approach which teaches theoretically supported strategies and skills to optimize specific cognitive functions*' and cognitive rehabilitation as '*an individualised approach using tailored programs centred on specific activities of daily life (in which) personally relevant goals are identified and the therapist, patient and family work together to achieve these goals*' (Simon et al., 2012). Examples of strategies taught in cognitive training include the use of memory aids, specific memory strategies and reminiscence therapy. Many studies and several reviews have reported that cognitive interventions appear to have beneficial effects in MCI, particularly in improving memory. The authors of the review mentioned above concluded that cognitive interventions appear to improve learning in aMCI but that it is difficult to be sure which aspects of the 'black box' interventions used in many studies, which were often multi-component, were responsible for this effect. They also commented that the effects observed in many studies related to the specific domain in which cognitive training had occurred rather than improving global cognition. A Cochrane review of the subject published in 2011 found that there was a significant improvement in recall in PWMCI who had undergone memory training but that this was only evident when they were compared to a 'no treatment' control group – there was no difference in recall when compared with an 'active' control group suggesting that the observed differences may not have been directly attributable to the memory training (Martin et al., 2011).

Another intervention which has been studied is the use of physical training. Studies in this area have shown some modest benefit on cognition but the results are somewhat clouded by the fact that positive results have frequently been gender-specific or only found when

physical training was used as part of an intervention package including cognitive training (Lautenschlager et al., 2010). A Cochrane review of this topic is currently underway.

Other studies have examined the effect of multicomponent interventions including aspects such as cognitive rehabilitation, psychoeducation, physical training and social activities. For example, Joosten-Weyn Banningh *et al.* carried out a study of a group based intervention in PWMCI and their carers which incorporated several of those features (Joosten-Weyn Banningh et al., 2011). They found no difference in measures of distress or general well-being in the intervention group compared to controls, although those receiving the intervention did show higher levels of acceptance. A Japanese study of 112 PWMCI attending 'dementia prevention classes', which involved 'exercise, recreation, creative activities or local excursions' identified modest overall improvements in cognitive function in at the end of the 3 months over which the classes were held (Ito and Urakami, 2012). However, as the authors pointed out, although there was an overall effect, when examined by geographical district not all classes resulted in cognitive improvements so it is not clear whether these results are widely generalizable or sustainable.

As part of the study of lived experiences of MCI described earlier, Lu and Haase carried out a qualitative exploration of the experience of spousal caregivers of people with MCI in which they interviewed ten people caring for spouses with MCI (at which point data saturation was reached). Based on the results of this and their other qualitative work on the subject (Lu et al., 2007a), Lu and Haase developed the 'Daily Enhancement of Meaningful Activity' (DEMA) programme for PWMCI and their caregivers (Lu and Haase, 2011). The programme has three main components:

- Six 'face-to-face' sessions for PWMCI and their caregiver with an advanced practice nurse, focussing on 'self-management' (i.e. provision of information about MCI, planning, management of negative emotions, available resources and strategies for minimising the effects of MCI)
- 'Homework' – completion of 'meaningful activities' and goals set in the face-to-face sessions
- Provision of a 'self-management toolkit' i.e. written educational material covering a similar range of topics to those in the face-to-face sessions

They assessed the validity, usefulness and acceptability of the programme using qualitative analysis of focus group discussions with 9 PWMCI and their spouses who had taken part in it; overall findings were positive. Participants stated that they wanted the programme to focus on self-management skills to help the PWMCI maintain independence (e.g. systems

for managing their own medication safely), communication skills (both between PWMCI and carers and with others), management of negative emotions and training in technology skills such as the use of mobile telephones and 'satnav' systems for navigating when driving. Participants supported the idea that such a programme should be accessed via physician referral.

2.2.4 Patient Reported Outcome Measures for Mild Cognitive Impairment

There is currently no consensus on the best way to assess needs or outcomes in MCI. A recent review of needs assessment instruments for use in mental and cognitive disorders concluded that *'there is a lack of instruments to assess the needs in individuals with subjective cognitive impairment (SCI), MCI or dementia comprehensively'* (Schmid et al., 2011). The authors identified and reviewed 17 instruments, most of which took the form of structured interviews or questionnaires; the majority were designed to assess the needs of patients with dementia or long term mental illness, none were designed specifically for use in MCI. The authors noted that, as patient reported unmet needs have been shown to correlate negatively with quality of life outcomes (QoL), tools designed to assess specific needs and hence guide appropriate interventions should be developed. They recommended that any needs assessment instruments developed should be based on a theoretical framework.

A review of patient self-reported measures for use in MCI identified a small number of patient-reported outcome measures (PROMs) used for the assessment of everyday function / ADLs, executive functioning, neuropsychiatric symptoms and health related quality of life (HRQL) (Frank et al., 2011). With the exception of the 'Patient Reported Outcomes in Cognitive Impairment' (PROCOG) tool (which is discussed in detail below) all other instruments identified were developed for use in other conditions (usually dementia) and adapted / validated to varying degrees for use in MCI. The authors noted that many of these tests fail to capture the subtle deficits which may be present in MCI and concluded that *'the time is right for the development of new patient-reported measures for MCI'*.

The PROCOG is a 55 item symptom impact questionnaire which was developed by Frank et al. (Frank et al., 2006a) for use in people with MCI and AD. The questionnaire was designed to assess basic symptoms and their impact on PWMCI's' lives. The process of development involved drafting an initial version of the questionnaire based on a review of the existing literature, the results of focus group discussions with patients and caregivers (Frank et al., 2006b) and discussion with an expert panel. The draft questionnaire was then reviewed by a small representative group of patients before further review by the expert panel and

modification to produce a final draft version of the questionnaire. The draft PROCOG was then field tested: It was validated against various neuropsychological measures in 78 PWMCI, 75 with mild probable AD and 33 cognitively intact controls and found to have good psychometric properties (Frank et al., 2006a). The stated aim of the PROCOG is '*assessing symptoms and patient rating of their impact on function, behaviour and HRQL*' and the authors suggested that the PROCOG might be used both as part of the neuropsychological diagnostic assessment process and in the assessment of needs for PWMCI and their carers. The questionnaire has subscales which measure affect, skill loss, semantic memory, recent memory, cognitive function, social impairment and long term memory. There are some limitations to the use of the PROCOG to assess outcomes in MCI in the UK: As described above the focus groups interviewed in the initial development of the measure and the patient panel who reviewed the first draft were comprised of both people with dementia and with MCI; as mentioned previously in this literature review the challenges faced by PWMCI and people with dementia have often been shown to differ significantly and therefore the use of a single instrument to assess outcomes in both these groups is questionable. The PROCOG was designed for patient use only, no assessment tool was designed for use by caregivers - a potential limitation given the finding in Frank's own study (and other studies) that PWMCI tend to under-report their problems when compared with informant reports. Although the focus group interviews with PWMCI were carried out at centres in both the United States of America (USA) and UK, no UK based informants were interviewed and validation of the PROCOG was carried out only in the USA. As there are important differences in the health and social care arrangements between these two countries it is unclear whether the PROCOG would be an appropriate tool for use assessment of PWMCI in the UK.

As mentioned above quite a number of scales to assess outcomes in dementia exist and these have been commented on in various arenas: A European consensus on outcome measures for psychosocial intervention research in dementia care, published in 2008, concluded that the most appropriate outcome measures for patients covered, between them, the domains of quality of life (QoL), mood, global function, behaviour and ADLs (Moniz-Cook et al., 2008). The authors identified the Quality of Life Alzheimer's Disease Scale (QOL-AD) (Logsdon et al., 2002) and the Dementia Quality of Life Instrument (DQOL) (Brod et al., 1999) as the measures of choice for the QoL domain. Some work has been done to establish whether these measures might be useful in MCI, for example, a group in Japan examined whether the QOL-AD, might be clinically useful in MCI (Tatsumi et al., 2011). They concluded that the scale did appear to be valid and reliable in this group. However, the study was small (involving 47 PWMCI and advocates) and conducted using the Japanese version of the QOL-AD, no similar studies have been conducted using the English language version.

The Alzheimer's Association (AA) published a report on PROs in dementia research in 2007 in which the use of such measures was discussed in light of the draft Food and Drug Administration (USA) (FDA) guidance on the subject which had been published the previous year (Frank, 2007). In the report the authors discussed the fact that, aside from recommending that proxy measures be used in cognitively impaired patients, the guidance made little reference to this patient group; recommendations were made about the future development of measures for use in this area. No similar reports on the use of PROMs in MCI have been published.

2.3 Caregivers' Experience of Mild Cognitive Impairment

2.3.1 General Experience of Caregiving in Mild Cognitive Impairment

2.3.1.1 Changes Noticed

Several qualitative studies of caregiving in MCI have been carried out and provide a description of the changes that such caregivers notice in the person for whom they are caring; those described most frequently across the literature were: behavioural changes, evidence of memory deficits and changes in the emotions expressed by PWMCI.

As part of the study of lived experiences described earlier, Lu and Haase carried out a qualitative exploration of the experience of spousal caregivers of people with MCI in which they interviewed ten people caring for spouses with MCI (at which point data saturation was reached) (Lu and Haase, 2009). They identified four major themes one of which was 'putting the puzzle pieces together: there really is something wrong'. This theme covered the changes caregivers noticed in their spouses such as short term memory loss, difficulty with familiar tasks and changes in behaviour, emotions and social activity. Behavioural change was also reported by informants in a mixed methods study of care partner responses to the onset of MCI (Blieszner and Roberto, 2010), Blieszner *et al.*'s study of spousal caregivers (Blieszner *et al.*, 2007) and Frank *et al.*'s qualitative study of PWMCI and mild AD (Frank *et al.*, 2006b)

Changes in personality and expressed emotion were also noted in a qualitative study of the experience of 10 family caregivers of PWMCI in Taiwan (Kuo and Shyu, 2010) and in Frank *et al.*'s study (where informants particularly reported increased expressions of anger by the PWMCI) (Frank *et al.*, 2006b).

2.3.1.2 Effects on Relationships

Several studies of caregiver experiences in MCI mention the effect on relationships with spouses, other family members and friends. For example, in Adams' study of carers in MCI and mild AD one of the main themes was 'changes in the relationship', such as increased protectiveness towards the PWMCI (Adams, 2006). On a positive note many spousal caregivers in this study noted that they had maintained a loving relationship with the PWMCI despite their cognitive changes.

Guided interviews with 67 married couples where one partner had a diagnosis of MCI were used to assess the impact on marital family life in study carried out in 2007 (Blieszner et al., 2007). The authors identified three key themes which were consistent with the theory of 'ambiguous loss' and noted that a diagnosis of MCI has far reaching effects for couples' relationships. The spousal caregivers interviewed reported changed roles within the home and relationship and increased relationship tensions (particularly where there had been pre-existing difficulties) – although the authors noted that most couples demonstrated a degree of 'resiliency' as they renegotiated their roles and relationships.

Another study focusing on the experiences of spouses of PWMCI examined self-reported measures of perception of marital quality, MCI related behaviour and caregiver burden in the spouses of 27 people recently diagnosed with MCI (Garand et al., 2007). Behaviours exhibited by PWMCI which resulted in the highest frequency-distress rating in caregiving spouses were: repetitive questioning, losing items and poor recall of recent events; these behaviours were all associated with lower marital satisfaction. Items reflecting disrupted communication between couples, such as 'decreased talk', were shown to be negatively associated with marital cohesion. Interestingly, marital quality was shown to be adversely affected by carer burden as described subjectively but not as assessed objectively.

Tellingly, the feelings about changes in their marital relationships that many of the caregivers in Lu and Haase's study described were summarised by the statement 'my best friend is gone' (Lu and Haase, 2009). The subjects in Adams' study also described a sense of loss of important elements of their relationship with the PWMCI – for example loss of a confidant or a parental figure (Adams, 2006).

2.3.1.3 Carer Burden

Some of the qualitative studies in this area have provided useful information on carer burden in MCI. The most commonly described elements of burden relate to increased carer responsibility for practical, everyday matters (such as driving and handling finances), increased supervision of the PWMCI and a resulting decrease in the carer's QoL.

One of the themes identified in Lu and Haase's qualitative study was 'the consequences to caregivers of living in a world of silence'. This incorporated the new responsibilities taken on by caregivers and their effects, for example: practical assistance with everyday function (e.g. providing supervision), increased decision making responsibilities and resulting detrimental effects on the caregiver's QoL (Lu and Haase, 2009). Frank *et al.*'s study also found that informants reported that PWMCI's roles within the family had changed and that they had become increasingly dependent. This resulted in substantial practical burdens on informants such as dealing with finances, driving and providing increased supervision (Frank *et al.*, 2006b). In keeping with these findings Adams' study of caregiving in early dementia and MCI also identified practical burdens on carers which included taking on new household tasks, managing finances and driving (Adams, 2006). The author noted that many of the interviewees described a '*struggle to decide how much to do for the person with memory loss*' and, particularly in the MCI group, difficulties with negotiating these decisions with the PWMCI. Blieszner *et al.* also noted that many spouses worried about whether the strategies they used to cope were the right ones (Blieszner *et al.*, 2007). In addition, these caregivers reported detrimental effects on their own social lives resulting from their increased caring responsibilities.

Other studies have examined caregiver burden more quantitatively: McIlvane *et al.*, as part of their questionnaire based study of people recently diagnosed with MCI, also surveyed 29 care partners about their experiences. They found that these care partners spent an average of 24 hours / week assisting the PWMCI (McIlvane *et al.*, 2008). A retrospective, notes based study of carers of 51 PWMCI found that about one third reported clinically significant perceived levels of burden and that increased burden was associated with a greater degree of cognitive impairment as perceived by both the PWMCI and carer and a with greater degree of depressed mood in the PWMCI as perceived by the carer (Bruce *et al.*, 2008). However, there was no association between carer burden and cognition as objectively assessed on neuropsychological testing suggesting that the *perceived* severity of the PWMCI's cognitive impairment has more effect on carer burden than the actual degree of cognitive impairment. Garand *et al.* also examined caregiver burden in their cohort of spousal caregivers of PWMCI (Garand *et al.*, 2005). They identified burden resulting from a wide range of areas such as household and nursing tasks in addition to perceived lifestyle constraints at levels greater than those reported by non-caregivers but less than reported by carers of people with dementia.

The results described above suggest that the subjects were caring for PWMCI with a relatively high level of dependency, something which might call the accuracy of their

diagnoses into question. However, in most of the studies cited above, MCI was diagnosed using the either Petersen, International Statistical Classification of Diseases and Related Health Problems 10th Edition (ICD-10) (World Health Organisation, 1992) or Clinical Dementia Rating (CDR) (Morris, 1993) criteria, usually following extensive neuropsychiatric and clinical evaluation in either a clinical or research setting. In the only study not to specify using one of these criteria (Blieszner's study of couples coping with MCI (Blieszner et al., 2007)) it was specifically stated that a diagnosis of dementia in their subjects had been ruled out. Therefore it seems likely that the subjects in these studies were indeed caring for people with MCI, rather than dementia or other disorders, despite the high level of dependency they displayed

2.3.1.4 Strategies and Coping

The final theme identified in Lu and Haase's study was 'taking charge of care'. This included a description of the coping strategies caregivers developed in the course of caregiving, such as practical approaches (e.g. use of reminder systems) and managing their own emotional distress (Lu and Haase, 2009). The strategies described in other studies can also be broadly divided into practical / problem focused and emotion focused: Practical coping strategies were identified in Blieszner *et al.*'s study where carers described creative approaches such as the use of reminder systems, redefinition of roles within the relationship and adaptation of the their daily routine (Blieszner et al., 2007). In McIlvane *et al.*'s questionnaire based study some carers also reported problem focused strategies (such planning for the future and seeking support) whereas others reported emotion focused coping (e.g. acceptance, humour) (McIlvane et al., 2008).

2.3.1.5 Emotional Consequences

Unsurprisingly, given the burdens on caregivers of PWMCI and the negative effects on their relationships described thus far, many studies have identified negative emotional consequences in this group.

One of the themes identified in Lu and Haase's study was 'a downward spiral into a world of silence' – this incorporated a description of intermittent periods of distress – both in response to the PWMCI's functional decline and as a result of family and friends' inability to understand the situation (Lu and Haase, 2009). Adams' study also identified negative emotional effects on carers, particularly frustration, impatience and anger (Adams, 2006). In both Kuo's and Blieszner *et al.*'s studies caregivers described uncertainty about the future coupled with anxiety about the possibility of the PWMCI developing dementia (Kuo and Shyu, 2010, Blieszner et al., 2007).

There has been some disagreement about the psychological impact on carers with MCI. Whereas the studies described above suggest an increased rate of NPS in MCI carers, a questionnaire based study found levels of depression and life satisfaction to be within normal limits (McIlvane et al., 2008). However, this study was small (29 carers were included) and secondary analysis of data for a much larger number of caregivers (769) from the Alzheimer's Disease Cooperative Study MCI trial identified depressed mood in nearly a quarter of all MCI care givers (Lu et al., 2007b) – a prevalence that was greater than in non-carers of a similar age (~13%) but less than in caregivers of people with AD (~ 40%). Factors associated with a greater risk of depressed mood were: fewer years of education in the carer and greater 'relational deprivation'. Younger, non-spousal caregivers were also at greater risk for depression.

Blieszner and Roberto's mixed methods study examined the relationship between depressive symptoms in carers of PWMCI and various demographic factors and other characteristics (Blieszner and Roberto, 2010). They identified clinically significant depressive symptoms in 12.5% of the study population (compared with 9% in the general population) and found that there was an association between depressive symptoms and poorer knowledge of dementia, being more bothered by the memory loss of the PWMCI, having a greater perceived level of burden and, interestingly, having a *greater* level of social support. Areas of stress identified included the PWMCI being less likely to initiate activities, changes in their sleep pattern, perseveration of 'unpleasant' behaviour such as repetitive questioning and memory problems compounding pre-existing issues such as physical ill-health. This was a relatively large study (with 86 subjects) which covered a wide range of issues using the mixed method approach; however, it is unclear whether depressive symptoms in isolation are a valid measure of carer experience. Garand's study also examined levels of depression as well as anxiety in carers of PWMCI; these were found to be at a level between those reported by non-carers and carers of people with dementia. Carer depression was associated with a greater responsibility for nursing tasks (such as administering medication) and anxiety with a greater perceived lifestyle constraint (for example carers reporting having a lack of time for themselves) (Garand et al., 2005).

The fact that the behaviour exhibited by PWMCI can negatively influence caregiver affect was confirmed in another study of spousal caregivers (Savla et al., 2011). In this study 30 spouses living with PWMCI were assessed over a seven day period using a checklist based telephone interview to assess daily stressors and affect as well as salivary cortisol levels as a marker of physiological stress. Negative affect in caregivers was found to be associated with behavioural problems occurring in the evening, unpleasant interactions with the PWMCI and decreased participation in scheduled activities on the part of caregivers. The authors

noted that it was these stressors which had the most impact rather than those related to caregiving per-se and as a result hypothesised that non-care related stressors affecting marital and social relationships may be the most significant in early cognitive decline. Caregivers who reported greater degrees of behavioural disturbance in their spouses were found to have higher levels of cortisol with less diurnal variation, consistent with a physiological stress reaction.

A fourth study (Roberto's study of family triads) also examined factors influencing the level of distress experienced by care partners of PWMCI (Roberto et al., 2011). The authors found that 'primary stressors' (such as witnessing changes in memory) and 'secondary stressors' (such as having to provide repeated reminders) were experienced by most care-partners regardless of the degree of acknowledgement of memory problems that they displayed. However, in families exhibiting a greater degree of acknowledgement care-partners were more able to assist the PWMCI in maintaining their previous activities and social contacts and seemed to cope with less distress. In families where acknowledgement was 'complete' or 'passive' care-partners were able to take on new responsibilities in a timely fashion whereas when acknowledgement was 'partial' or 'absent' the PWMCI often appeared reluctant to accept their changing role and care-partners reported feeling overwhelmed by trying to manage new responsibilities in this context. Moreover, the degree of discrepancy between acknowledgement in the PWMCI and their care-partner was important: where discrepancy existed it was most commonly due to a lack of acknowledgement on the PWMCI's part and this often resulted in a degree of resistance to accepting support from 'outside' sources thus resulting in increased care-partner distress.

2.3.1.6 Attributions

Like PWMCI, carers' attributions for the changes they observed varied widely in the studies reviewed; they included many of the same explanations described by PWMCI, although carers described being uncertain as to the cause of such changes more frequently than the PWMCI did. For example, Blieszner *et al.*, in their interviews with married couples, found that many experienced a period of uncertainty during which they were unsure whether there was a significant problem or not. During this period spouses attributed the changes they had noticed to a variety of causes – both 'external, uncontrollable' (such as 'getting older' and physical health problems) and 'internal, controllable' (such as laziness or poor concentration) (Blieszner et al., 2007). Frank *et al.* also identified diagnostic uncertainty in the MCI informant group (Frank et al., 2006b).

Aside from uncertainty, carers described a variety of attributions including 'normal ageing' – as in Blieszner *et al.*'s study and the study of Taiwanese caregivers which concluded that

they tended to use a process of ‘ambivalent normalisation’ to adjust to the changes observed in PWMCI. As part of this process many compared the PWMCI’s condition with that of their peers (or even themselves) and concluded that the changes observed were part of normal ageing (Kuo and Shyu, 2010).

Physical health problems were also commonly cited as an explanation for cognitive symptoms – for example in Bleiszner *et al*’s study and that of the ‘family triads’, where subjects were roughly equally split between those who attributed the changes in the PWMCI to a physical health problem, those who attributed it to a primary cognitive problem and those who attributed it to aspects under the PWMCI’s control e.g. concentration (Roberto *et al.*, 2011).

Finally, as mentioned above, it was not uncommon for informants to attribute the changes they had observed to factors under the PWMCI’s control – such as the amount of effort or concentration a person put into remembering something (Blieszner *et al.*, 2007, Roberto *et al.*, 2011).

2.3.1.7 Comparison With Caregiving in Early Dementia

The burdens associated with caring in dementia have been extensively studied. A review of the literature published in 2000 described the varied patient and carer factors that have been shown in different studies to be associated with carer burden and stress (Burns and Rabins, 2000). The most consistent of these, identified in several studies, appeared to be personality change and behavioural disturbance in the patient and level of expressed emotion in the carer. The commonest manifestation of carer stress was found to be depression which was identified in up to 70% of carers.

It is far from clear, however, whether the findings of studies of caregiving in dementia are applicable to caregiving in MCI. In fact, it is likely that carers of PWMCI face a number of different issues from dementia caregivers, for example the fact that a diagnosis of MCI carries a much greater degree of prognostic uncertainty than one of dementia and that these carers are at a much earlier stage in their caregiving career so may not yet have adapted to their new role. It is also likely that the different manifestations of MCI and dementia result in different challenges for caregivers. For example, in a study of dependence and caregiver burden in AD and MCI functional impairment was found to predict caregiver burden in the MCI group whereas the severity of NPS was the only predictor of burden in the AD group (Gallagher *et al.*, 2011). In contrast, a study involving semi-structured interviews with twenty carers of PWMCI and dementia identified no significant differences in the experiences of carers in each group (Adams, 2006). However, as the study sample included only 3 subjects

with MCI it is difficult to be sure that data saturation would truly have been reached for this group and consequently there may have been issues relevant to the MCI carer group not identified by this study. A review of published literature on the subject of caregiver burden in MCI noted that the studies reviewed had, on the whole, used the same concepts and theoretical constructs as studies of caregiving in dementia and that this approach may well be flawed due to the fact there are many aspects of caregiving in MCI which are unique (Werner, 2012). The conclusion to the review included the recommendation that further qualitative or mixed-method studies should be carried out in this area to gain a better understanding of the issues which are specific to MCI carers.

Finally, it is important to remember that the extensive network of formal and informal support available for people with dementia and their carers is not available to most PWMCI or their carers and that this may increase levels of perceived burden amongst caregivers.

2.3.2 Caregivers Experiences of Healthcare and Support Services

Much less work has been done on the topic of caregivers' experiences of healthcare than on the experiences of the PWMCI themselves. However, some of the studies of PWMCI's experiences of healthcare have also examined those of their carers: In the study of patients and caregivers attending their first memory clinic assessment the carers, like the patients, reported that they found the wait between referral to memory clinic and the appointment a distressing and unsettling time (Cahill et al., 2008). Unlike the patients (who reported a general desire to be 'helped' by the clinic), carers in this study reported that they hoped for specific outcomes as a result of the assessment process, most commonly identification of the cause of memory problems or provision of treatment. In the Dutch study of patients and carers attending memory clinic the levels of satisfaction with communication of results, the usefulness of assessment and the clinician's attitude were equally high in the carers and the patients (70-80% of both groups reported satisfaction with these aspects of their care), however carers reported being less satisfied with the advice and support that they received (with only ~20% giving a positive rating on this topic) (van Hout et al., 2001).

In Blieszner *et al.*'s study of married couples many reported receiving 'vague' information about MCI from their physicians and consequently some had sought information from other sources such as the internet or public libraries (Blieszner et al., 2007). Those who did so reported finding very little information specific to MCI aimed at the general public. In the study of family caregivers in Taiwan many reported 'unintentional helpseeking' i.e. learning the diagnosis of MCI via a process of assessment begun when the person sought medical care for another (usually physical) condition (Kuo and Shyu, 2010).

2.3.3 Suggested Interventions

Increased Support Needs

Several studies have identified a need for additional support for carers of PWMCI: In a study comparing the support service needs of carers of PWMCI with those of cognitively normal controls and people with probable AD a similar need for support services was identified in the carers of PWMCI and those of people with probable AD, this was greater than the support needs of carers of normal controls (Ryan et al., 2010). The term ‘support services’ encompassed medical, social, community and mental health support. Assessment of support needs and the attributes of the PWMCI was achieved by the use of several quantitative scales, such as the NPI, meaning that the analysis of the reasons for the elevated support needs in the MCI care group was limited. However, a correlation was found between the support needs of carers in the MCI group and the degree of frailty of the PWMCI as well as with the number and frequency of NPS they displayed.

The theme ‘taking charge of care’ identified in Lu and Haase’s study included a description of the needs reported by carers (Lu and Haase, 2009). The major categories of needs described were: information about MCI and development of skills in communication, caregiving skills and managing distress in the PWMCI and themselves. Adams’ interviews of caregivers revealed ambivalence in some about seeking both formal and informal support – often due to concerns about placing burden on other family members or the opinion that it was ‘too early’ in the course of the disease to seek formal help (Adams, 2006).

Relevant Studies in Dementia

A great deal of research into caregiver interventions in dementia has been published and forms a useful backdrop for designing potential guidance for services managing PWMCI and their carers. For example, Burns and Rabin’s review of carer burden in dementia (Burns and Rabins, 2000) (which included outcomes other than burden rating scales) concluded that there is evidence that interventions aimed at both patients and carers can reduce behavioural problems, improve mood in both patients and carers and decrease rates of nursing home placement in dementia. The most effective interventions reviewed appeared to be those directed at behaviour, often in the form of family or individual counseling or support groups. A meta-analysis of 127 controlled intervention studies in dementia caregivers also identified small but significant effects on burden, depression, subjective well-being, ability and knowledge ratings following caregiver interventions (Pinquart and Sorensen, 2006). Active participation in psycho-educational programmes in which information about dementia and caregiver support was provided seemed to be the most effective intervention. A reduced

risk of admission to long term care was also identified, but only following multicomponent interventions (i.e. those combining at least two types of intervention). The authors caution, however, that the effect sizes where identified were small and tended to diminish with time (particularly in the case of subjective well-being). As discussed above, however, the applicability of the finding of these studies to caregivers of PWMCI may well be limited.

Suggested Interventions

Few studies have assessed the efficacy of interventions specifically for caregivers for people with MCI. However, several of the observational studies which have focused on the difficulties faced by PWMCI and their carers have included recommendations for interventions that might prove effective in light of the study's findings – a number of which recur across the literature:

A common recommendation was the provision of information about various aspects of MCI, for example as recommended by Joosten-Weyn, Adams and Kuo and Shyu following their studies of PWMCI (Joosten-Weyn Banningh et al., 2008, Adams, 2006, Kuo and Shyu, 2010). Austrom and Lu conducted a review of the literature about caregiving in MCI and relevant work on assisting carers of people with early dementia (Austrom and Lu, 2009) in 2009. They noted that the evidence for effectiveness of educational and psychological interventions in people caring for patients with AD had been mixed. Nonetheless, they made several recommendations regarding interventions in MCI including that information about sources of legal and financial advice should be offered and that carers should be educated about the nature of MCI. Blieszner *et al.* also advocated the provision of information specific to MCI, both in print and on the internet, covering topics such as the cause, helpful interventions for symptoms and techniques which might be employed to allow PWMCI to live as full a life as possible (Blieszner et al., 2007). The authors of the study of family triads suggested that, in light of their findings, information and support might be tailored to the type of acknowledgement displayed by the family: Where acknowledgement is limited they postulated that the provision of detailed information about the pathogenesis of MCI and guidance on management and sources of support would be helpful (Roberto et al., 2011).

Like Blieszner *et al.*, several authors recommended that, in addition to basic information about MCI, caregivers should be provided with strategies to assist the PWMCI and enhance coping in everyday life. For example, both Austrom and Lu and Lu *et al.*'s papers recommended that family caregivers should be advised on how best to assist PWMCI in remaining independently engaged in their usual activities and social networks (Lu et al., 2007a, Austrom and Lu, 2009) and the authors of the Taiwanese study recommended that caregivers should be helped to develop strategies to avoid conflict with the PWMCI. The

conclusions of the study on daily stressors, psychological well-being and cortisol levels in spouses of people with MCI suggested that, in light of their findings (which suggested a physiological stress reaction in this group of caregivers), efforts should be made to teach effective stress management to this group (Savla et al., 2011). The authors of the study of family triads suggested that advice on the development of useful strategies might be helpful for caregivers where there is full acknowledgement of MCI (Roberto et al., 2011).

Another common recommendation in the literature was the provision of psychosocial training or support to caregivers (Joosten-Weyn Banningh et al., 2008, Adams, 2006). In their review Austrom and Lu recommended that attention should be paid to psychological health via the provision of family therapy and / or support groups and that education of both carers and PWMCI should include information about the features of depression with encouragement to seek assessment should they develop symptoms (Austrom and Lu, 2009). The authors of the study of couples coping with MCI also recommended group and individual interventions such as family therapy, counseling and MCI specific support groups (Blieszner et al., 2007).

Many authors emphasised the importance of *early* assessment and intervention for caregivers. For example Austrom and Lu recommended that information should be offered to caregivers early on as part of an emphasis on planning for the future (Austrom and Lu, 2009), Blieszner *et al.*'s and Adams' papers both recommended that psychosocial interventions should be offered early (Blieszner et al., 2007, Adams, 2006) and Savla recommended that stress management skills be taught at the beginning of the caregiving career (Savla et al., 2011). Lu and Haase also recommended that any interventions should be offered early in order to capitalise on the period when the insight of the PWMCI is preserved (Lu et al., 2007a).

In their study of spousal caregivers of PWMCI Lu and Haase noted the lack of proven interventions for this group and concluded that *'there is a critical need to develop an early intervention that can help MCI patient-carer dyads modify behaviour, compensate for deficits, and minimize negative outcomes from conflicts associated with those deficits'* (Lu and Haase, 2009). The resulting DEMA programme designed for use in both PWMCI and their caregivers is described in the section on 'Patient Experiences of Healthcare and Support Services - Suggested Interventions and Support' (Lu and Haase, 2011). In the study examining validity of the DEMA, in addition to the general comments on content, the caregiver focus group made specific recommendations about the format of educational material provided (e.g. the avoidance of abbreviations in material designed for the PWMCI) and requested that they be provided with separate information to the PWMCI with more advanced content. The authors concluded that their findings *'support the importance of*

integrating family members into interventions designed for PWMCI, because it provides a foundation of support as family members move to a greater caregiving role.'

2.3.4 'Self-Reported' Outcome Measures for Carers of People with Mild Cognitive Impairment

No articles on self-reported outcome measures for use in caregivers of PWMCI were identified by the literature review. Some work has been done on this topic in dementia caregivers, for example the authors of the 'European consensus on outcome measures for psychosocial intervention research in dementia care', as well as examining the most appropriate outcome measures for patients, also commented on the best scales to use for their caregivers (Moniz-Cook et al., 2008). The measures they identified for use in family caregivers covered the domains of mood and burden (incorporating coping and QoL) with those measuring QoL falling into two categories: 'generic' health-related QoL scales such as the Short Form Health Survey (SF) scales (Ware and Sherbourne, 1992) and disease specific measures. They commented that, while many of the health related QoL scales had good psychometric properties they had not been validated specifically for use in caregivers of people with dementia. Disease specific scales were also mentioned, such as that developed in the French PIXEL study (Thomas et al., 2006), but it was noted that these required further validation before their use could be recommended. Whilst it may be that general health related QoL scales could be used as a valid measure of QoL in carers of PWMCI there is no published literature to support this, nor have any disease specific, self-reported scales for measuring outcomes in this group been published.

2.4 Limitations of the Studies Discussed

Most studies reviewed here examined the experiences of spousal caregivers which limits the information available on issues relevant to non-spousal caregivers such as grown-up children. Non-spousal caregivers are likely to experience a different set of concerns given that their circumstances tend to be different from spousal caregivers e.g. they usually live separately from the PWMCI and often have additional responsibilities such as childcare and employment. The Alzheimer's Disease Cooperative Study (Lu et al., 2007b) did find that that younger, non-spousal carers had greater rates of depression which supports the hypothesis that the experience of caregiving is different in some way for non-spousal carers.

Another limitation common to most of the studies reviewed is that subjects were almost exclusively Caucasian - there is very little information about carer experiences in ethnic minorities. Although several of the studies were carried out in countries other than the UK or USA (e.g. Holland and Taiwan) no subjects in these studies were 'ethnic minorities' in this

context as all interviewees were living in their country of origin. Most of the themes identified in studies conducted in the various countries were similar or identical with only occasional exceptions – such as the phenomenon of ‘unintentional help seeking’ which was only identified in the study conducted in Taiwan. This may reflect cultural differences in attitudes to illness and interaction with health services.

All these studies, including those employing quantitative research methods, had relatively small sample sizes and most were observational, meaning that limited conclusions about causality are possible. Most studies were cross sectional in design therefore little is known about how the experiences and support needs of PWMCI and their carers change over time.

2.5 Summary

Evidence regarding the experiences of PWMCI and their carers is limited and evidence for successful interventions in this group almost non-existent (although some studies in patients with early dementia may be relevant).

The studies which have been done suggest that PWMCI experience a range of cognitive, neuropsychiatric and practical issues (such as difficulty completing complex ADLs). They face uncertainty about their condition and about the future and, in the face of this, often attribute their symptoms to ‘normal ageing’. It may be that PWMCI under-report their problems due to reduced insight secondary to their MCI. Carers experience a range of emotions (mainly negative) and new responsibilities for which they are obliged to develop practical solutions. Relationships between PWMCI and carers often change as they adapt to their new roles and carers face significant uncertainty about the future.

Few studies of cognitive or psychosocial interventions have been carried out in MCI; those which have been done have found that psychoeducational and multicomponent programmes have been most successful in improving outcomes for patients. Various strategies have been suggested by the authors of the observational studies of MCI reviewed here. The most commonly suggested interventions include provision of information about MCI and practical matters such as sources of legal and financial support, psychosocial training (via individual counseling or support groups) and the teaching of strategies to enhance communication skills and coping. Most authors emphasise the importance of early, individualised needs assessment and intervention. Only one PROM designed specifically for use in MCI exists and this was developed in a mixed sample of PWCMI and AD, no equivalent measures exist for use in caregivers of PWMCI.

In conclusion, the findings described here suggest that there is a need for a focused exploration of the experiences of people living with MCI and their carers, with particular

reference to healthcare, so that valid outcome measures can be developed to evaluate the health of these groups and appropriate improvements to services may be suggested.

Chapter 3: Interviews

3.1 Introduction

In the first part of the study in-depth, semi-structured interviews were carried out with people with mild cognitive impairment (PWMCI) and their advocates in order to gather detailed information about the experiences of these groups. In the first part of this chapter the interview methodology is described – including details of the development of the interview topic guides, recruitment of study subjects, conduct of the interviews and analysis of the resulting data. The advantages and limitations of the methods used are also discussed. In the second part of the chapter the results of qualitative analysis of the interview data for patients and advocates are described. In the final part of the chapter the results of the patient and advocate interviews are discussed and compared, both with each other and with the existing literature on the topic

3.2 Interview Methodology

3.2.1 Development of Interview Topic Guides

Initial topic guides for the patient and advocate interviews were developed based on the themes which had been found to recur frequently in the literature review described in Chapter 2. The broad areas covered by the interview guides for both groups were: the impact of mild cognitive impairment (MCI) on subjects' daily life, their experiences of healthcare services (both the general practitioner (GP) and Memory Services), suggested improvements to these services and their current sources of information and support. An iterative process was used to alter the topic guides to include novel subjects introduced by interviewees as the interviews progressed. The final topic lists for patient and advocate interviews are given in Appendix 1

3.2.2 Recruitment

A purposive sample of PWMCI was identified from memory clinics (and 'analogous services') in the UK in Oxfordshire, Buckinghamshire, Berkshire, Northamptonshire and Essex, from research databases in Oxfordshire and Essex and via advertisements (in the form of posters and patient leaflets) placed in clinical areas in these regions. 'Analogous services' were defined as 'equivalent memory services being provided outside the 'traditional' setting of a hospital outpatient memory clinic', for example services provided in the patient's home by community mental health teams (CMHTs).

PWMCI included were aged 50 years or older and had all been diagnosed with MCI in a memory clinic (or analogous service), using the clinical criteria applied by the clinician making the diagnosis, within 6 months of recruitment. In addition, eligible subjects had an absence of: any significant barrier to communication, current 'International Statistical Classification of Diseases and Related Health Problems' (ICD-10) based major psychiatric disorder or clinically significant or unstable medical condition that could account for their cognitive deficits.

Patients recruited from clinic were approached at their appointment with initial information about the study. If they expressed an interest in taking part in the study they were asked to complete a form giving their contact details and consent for their medical notes to be viewed for the purposes of research. The details were passed on to the author who screened each patient's medical notes to ensure that they were eligible for inclusion in the study (as per the criteria above). Patients who were eligible were sent full information about the study by post and contacted by telephone two weeks later to arrange an appointment for interview.

Patients who had been clinically assessed within 6 months and diagnosed with MCI were identified from the following research databases:

- Derwent Memory Clinic Research database
- The 'Dementia and Neurodegenerative Diseases Research Network' (DeNDRoN) research database for Oxfordshire Health Trust
- The 'Dementia Electronic Prescribing and Research Contact System' (DEEPARC) database
- The 'Oxford Project to Investigate Memory and Aging' (OPTIMA) database.

All patients with details recorded on these databases had given prior written consent to being contacted for the purposes of research. Patients identified from the database were sent full information about the study by post, including a form to complete giving their contact details and consent for their medical notes to be viewed for the purposes of research which they were asked to return if they were interested in taking part in the study. When reply forms were received the author screened each patient's medical notes to ensure that they were eligible for inclusion in the study (as per the criteria above). PWMCI who were eligible were then contacted by telephone to arrange an appointment for interview. PWMCI who did not return a reply form within two weeks of being sent full study information were sent a reminder letter; if no reply form was received subsequent to this they were not contacted about the study again.

PWMCI who contacted the researcher having seen an advertisement for the study were sent full study information by post and recruitment proceeded as for PWMCI identified from the research databases as described above.

Advocates were recruited via PWMCI. An advocate was defined as 'a relative or friend who the patient felt had been affected by their memory problems' (often a spouse or other family member). When the PWMCI was sent full study information by post an 'advocate recruitment pack', comprising an information sheet, covering letter and reply form was included. When the patient was telephoned to arrange an interview they were asked whether they were in contact with anyone who might be a suitable advocate whom they would be happy for the researcher to interview. If the patient identified a suitable advocate they were asked to pass the 'recruitment pack' on to that person. Information included in the 'recruitment pack' instructed the advocate to complete the reply form with their details and return it to the researcher if they wished to take part in the study. When the reply form was received by the author the advocate was telephoned to arrange an interview.

Examples of the relevant study literature – including information sheets and consent forms – are included in Appendix 2.

Interviews were continued until data saturation was reached i.e. the point at which new interview data provided no new information in terms of codes identified by qualitative data analysis. It was hypothesised, based on the previous experience of one of the supervisors of this research (CJ), that this would occur after approximately 25 patient and 25 advocate interviews and this was therefore the recruitment target.

3.2.3 Conduct of Interviews

Approval for this study was obtained from the Southampton and South West Hampshire Research Ethics Committee (REC) (B) and the Research and Development (R&D) Departments of each hospital trust involved. Written informed consent was obtained prior to each interview.

Semi-structured interviews were conducted with PWMCI and advocates at a location of their choosing: either their home, the home of a friend or relative or a hospital outpatient department. Interviews were conducted in a private room and PWMCI and advocates were interviewed separately (unless both expressed a strong desire to be interviewed together) in order to maintain confidentiality and encourage freedom of expression. Respondent validation was carried out towards the end of each interview by summarising the key points of the discussion and confirming that the subject agreed with their accuracy. In addition to the semi-structured interview the 'Hospital Anxiety and Depression Scale (Zigmond and

Snaith, 1983)' (HADS) was administered to PWMCI and information was collected (either from patient notes at screening, or via the information gathered at interview) as to whether the Petersen criteria (Petersen et al., 2001b) for diagnosis of MCI were fulfilled. The Mini Mental State Examination (MMSE) score (Folstein et al., 1975) at the time of diagnosis was also noted if this was available in the subject's clinical notes at screening.

Interviews were recorded and analysed anonymously with only the author aware of the identity of each subject. The majority of interviews (19 of those with PWMCI and 17 those with advocates) were carried out by the author in order to maintain consistency in questioning style and topics. At one point during the recruitment process there was a high volume of simultaneous referrals and therefore another interviewer completed some interviews: four patient and two advocate interviews were carried out by Mrs Claire Merritt (CM) who had extensive experience both in community psychiatric nursing and research, including conducting semi-structured interviews. Most interviews lasted between 30 minutes and one hour.

Where scores from the HADS suggested symptoms of anxiety or depression of moderate severity or greater the subject's GP was informed in writing (if the subject consented to it). The subject's GP was also informed (again, with the subject's consent) if any issues were identified during the interview with which either the subject or interviewer felt the GP could be of assistance.

3.2.4 Data Analysis

The audio-recorded interviews were professionally transcribed and the transcripts checked for accuracy by the researcher who read each transcript whilst listening to the audio file. Transcripts were then coded by the researcher in a two stage process using an inductive approach: in an initial line-by-line reading, open coding was used i.e. the concepts identified were given labels ('codes') and categories were developed into which these concepts were grouped. Once this initial process was completed, an analytic framework was developed and focussed coding of the transcripts was carried out using this framework i.e. codes and categories were eliminated, combined or subdivided as recurring ideas and underlying themes connecting the codes were identified. NVivo software (version 9) was used to organise the data and assist with analysis. This thematic analysis was conducted in parallel with the interviews to allow monitoring for data saturation and addition of any new themes emerging from the data to the interview topic guide.

3.2.5 Discussion of Methodology

3.2.5.1 Advantages of Method and Methodology

The overall approach used in the study, (i.e. in-depth interviews and, later, subject questionnaires), was chosen so that a detailed picture of subjects' own experiences might be built up. Grounded theory methods were chosen as the most appropriate approach for the first part of this study (to generate items for the outcome measures and healthcare experience survey) as there has been relatively little research in this area and hence existing information about the concerns of PWMCI and their advocates is limited i.e. it is an undocumented phenomenon. The use of semi-structured interviews allowed subjects to raise issues of importance to them whilst ensuring that information about matters of particular interest to the researcher, such as healthcare services, was also gained.

The PWMCI in this study were recruited from a number of sources in various geographical areas with different healthcare arrangements. As a result the subjects recruited had had experience of a range of services and the study results are more broadly applicable than had recruitment been from a single clinic. Advocates were recruited via PWMCI to ensure that patient confidentiality was maintained. No advocate was interviewed without express verbal and written consent from the linked patient and no advocates were interviewed unless a linked patient was taking part in the study.

The inclusion criterion that PWMCI should be 50 years of age or older was selected to maximise the likelihood that the diagnosis was accurate as it is known that the incidence of MCI increases with age (Ritchie, 2004, Luck et al., 2010b) hence the pre-test probability of MCI is greater in older patients. The criteria that subjects should not have significant medical or psychiatric comorbidities were also chosen to increase the probability that the MCI diagnosis was accurate. That subjects must have been diagnosed with MCI not more than six months before recruitment was stipulated in order to maximise recall of subjects' concerns before and around the time of diagnosis and to minimise the risk that the subject might have developed dementia prior to interview. Evidence suggests that in MCI cognitive scores such as the mini-mental state examination (MMSE) tend to remain relatively stable over a 6 month period (Petersen et al., 2001b). It was important that subjects had no significant barrier to communication to allow a fluent interview process and accurate transcription and analysis. A diagnosis of MCI made using the criteria used in the clinic (rather than one based on research criteria) regardless of subtype was used for the inclusion criteria to ensure that the study results would be as widely applicable to actual clinical practice as possible. Due to the nature of recruitment and the referral process, explicit

details of the diagnostic criteria applied were not always available. However, in those cases where these details were obtained (e.g. where the clinical notes gave sufficient information) it appeared that most clinicians had applied criteria similar to the Petersen criteria i.e. subjective memory complaint, cognitive impairment on testing, largely intact activities of daily living and not meeting the criteria for dementia. Advocates were defined as *any* friend or relative the patient felt had been affected by their MCI so as to broaden this category as much as possible and not limit it to spouses who have been the main focus of research into 'caregiving' in MCI thus far.

Where possible, interviews with PWMCI and their linked advocates were carried out separately. This allowed preservation of confidentiality and encouraged subjects to speak freely, often broaching subjects they might not have done in presence of study partner. Indeed, it was noted that some subjects lowered their voices when discussing sensitive topics during interviews indicating that they did not wish to be overheard and suggesting that they would not have discussed that particular issue in the presence of the linked subject. Separate interviews allowed comparison of the attitudes and understanding within PWMCI-advocate dyads. This approach also allowed discrepancies in the accounts of linked study partners to become apparent, unlike in joint interviews where each may have been influenced or prompted by the other's responses.

Although the inclusion criteria stipulated that diagnosis of MCI could be made by whichever criteria were used by the diagnosing clinician, information about whether each patient met the diagnostic criteria described by Petersen was collected in order to allow comparison of the results of this study to other work in the field (as Petersen's criteria are the most commonly used in research). Information about symptoms of anxiety and depression was collected for each patient using the HADS. This allowed analysis of the incidence of these neuropsychiatric symptoms (NPS) in the MCI group.

Respondent validation was carried out during the interviews i.e. the information that had been discussed was briefly summarised by the interviewer and repeated back to the interviewee in order to verify accuracy. This process helped maximise the accuracy and internal and external validity of the findings.

Interview data were analysed inductively (as per grounded theory); this allowed subjects' opinions to determine the results of the first part of the study and hence dictate the content of the resulting questionnaires as far as possible. The overall approach used in this study, including inductive analysis, was chosen to allow the development of outcome measures that are patient (or advocate) response guided. Coding was primarily carried out by the author and she maintained overall responsibility for coding to ensure consistency was

maintained. The emerging coding scheme was reviewed and discussed with other researchers experienced in this field until 100% agreement was reached.

3.2.5.2 Limitations of Method and Methodology

ETHICAL APPROVAL AND RECRUITMENT

The process of obtaining ethical and research approval from the REC and the R&D departments of the five different hospital trusts involved was time consuming and involved a heavy administrative burden. Some difficulties with recruitment occurred as a result of the burden of paperwork, mandated by REC guidance, which involvement with the study incurred for research staff and participating subjects. For example a 'double-consent' process was requested by the ethics committee, this involved all interested potential participants having to complete an 'initial' consent form to indicate that they consented to being contacted by the author. As a result, staff at some participating sites were reluctant to take part in recruitment because it involved seeking this 'informed consent' and there were some administrative challenges involved in ensuring that all sites had supplies of the appropriate paperwork. Participants recruited from research databases were sent a large volume of paperwork comprising a covering letter, information sheet, consent to contact form and information for their linked advocate which included the logos of both the local NHS trust and the study sponsor (the University of Oxford). For some potential participants this caused some confusion and reluctance to take part in the study. Some of the participants with MCI also found the process of having to complete the initial consent form and return it by post confusing and delegated this to their advocate.

In some of the centres involved in recruitment to the study it was routine practice for the diagnosis to be made following a multidisciplinary team meeting after the patient's initial clinic assessment but for the diagnosis not to be communicated to the patient until their follow up appointment which usually occurred six months after the initial appointment. This meant that by the time the patient was aware of their diagnosis they were no longer eligible for the study as the diagnosis had been made more than 6 months previously.

Several methods were adopted to increase recruitment in the face of the challenges described above: Where clinic patients expressed an interest in taking part in research but recruitment paperwork was not available in clinic or there was insufficient time to complete it research staff and clinicians were encouraged to enter the patient's details onto the local research database (with their permission) and inform the author that this had occurred. The author was then able to approach the patient via the research database. In some areas subjects listed on research databases were contacted by a local member of research staff by

telephone to give them some brief information about the study and find out whether they would be interested in receiving information about it. This helped to address the issue of subjects being unclear about why they had been contacted about the study, particularly for those not in the Oxford area. About half way through the recruitment process a teleconference was held with research staff from participating sites in order to remind them about the study and discuss approaches for increasing recruitment.

INTERVIEW PROCESS

A potential limitation of interviewing subjects some time after diagnosis is that the anxieties and uncertainties engendered by their memory problems may have been dispelled at the time of diagnosis and be difficult to recall several months later. However, existing evidence (Frank et al., 2006b, Lu et al., 2007a, Kuo and Shyu, 2010) suggests that one of the attributes particular to receiving a diagnosis of MCI is the uncertainty this causes and it therefore seems unlikely that subjects would have no further concerns after receiving this diagnosis.

The recruitment procedure may have resulted in an element of selection bias in that those people who had experienced greater dissatisfaction with healthcare services may have been more likely to respond to the invitation to take part in the study so that they could have their complaints heard. However, the data from the interviews does not suggest that a large proportion of the PWMCI interviewed were particularly dissatisfied with the care they had received.

On interviewing PWMCI, particularly when comparing their responses with those of linked advocates', it became apparent that many had difficulty recalling the diagnostic process and some had limited insight into their difficulties. Although this limited the information about the exact process of assessment at memory clinic which could be obtained from the PWMCI, the fact that many had little recall of what was often a fairly lengthy diagnostic process was an interesting finding in itself. As most PWMCI had a linked advocate with good recall of the medical assessment process the advocates were usually able to supply at least some of the details which the PWMCI was unable to remember. It also became apparent during the interviews that not all subjects, in fact very few of them, were aware of the term 'mild cognitive impairment' as applied to the PWMCI's memory problems. Although this limited discussion of their understanding of the term this finding is a valid comment on the diagnostic disclosure process.

It was noted, particularly in early interviews, that subjects had a tendency to continue talking about relevant topics after the interview had been officially concluded and the audio-

recording stopped. In early interviews this was addressed by the use of additional field notes to capture these issues, the notes were subsequently transcribed and uploaded to NVivo for coding. In subsequent interviews efforts were made to make the audio-recording process as unobtrusive as possible to remove the distinction between the artificial setting of 'the interview' and more general conversation, in which the subject might be more relaxed and expansive. The interview procedure was also altered so that audio-recording was continued until the subject (or interviewer if the interview was has taken place at the subject's home) was preparing to leave to ensure that all relevant comments were captured as far as possible.

Another phenomenon noted in early interviews was that of the interviewer (the author) being perceived by subjects in a 'doctor role' which resulted in subjects asking her questions about medical issues. This had the effect of interrupting the subject's narrative and introduced the risk that the interviewer's answer would influence the subject's subsequent responses. In order to address this difficulty, the interviewer's introductory comments were modified to shift emphasis away from her being a 'clinical doctor' onto being a 'researcher'. In addition subjects were asked to keep any clinical questions for the end of the interview at which point the researcher gave general information where appropriate or directed subjects to their own healthcare provider. Administration of the HADS questionnaire, which has a somewhat 'medical' emphasis, was moved to end of interview in order to avoid introducing medical connotations at the beginning of the session. The additional researcher (CM) who carried out some interviews during a period where quite a number of simultaneous referrals were received at once was not a medical doctor. The themes apparent in the interviews conducted by CM were not substantially different to those in the interviews carried out by the author – this suggests that the adjustments described above did prevent subjects from being unduly influenced by the author's medical background.

Although the majority of subjects agreed to be interviewed separately some PWMCI-advocate dyads wished to be interviewed together. Although these interviews remained revealing it was more difficult to get an accurate picture of each subject's individual recollections and concerns, particularly as the PWMCI tended to defer to advocates in matters where recall of particular events was required e.g. the process of assessment at memory clinic. One positive aspect of interviewing PWMCI and advocates together was the enhanced opportunity it provided to detect discrepancies between recall of events on the part of the PWMCI and their linked advocate.

DATA ANALYSIS

Although it is not possible to conduct this type of qualitative analysis without some degree of bias resulting from background reading and personal experiences the effect of this was minimised by remaining vigilant for undue prejudice whilst analysing the data.

3.3 Interview results

3.3.1 Descriptive Results of Interviews of People with Mild Cognitive Impairment

3.3.1.1 General Description of Interviews

In total 23 semi-structured interviews were carried out with people with mild cognitive impairment (PWMCI), 19 of these were conducted by the author and 4 by another researcher (CM). 19 of the interviews were carried out with the subject alone and 4 in the presence of the advocate. Interview durations ranged from 15 – 52 minutes, with a mean of 31 minutes. Participants were aged between 63 and 86 years old with a mean age of 77.8 years. Thirteen interviewees were male and 10 were female, all were of White British origin. Mini-mental state examination (MMSE) (Folstein et al., 1975) scores were available for 14 of the subjects interviewed, the mean MMSE for these subjects was 26.9 (range 22 – 30). Sixteen of the subjects met the Petersen diagnostic criteria for mild cognitive impairment (MCI) (Petersen et al., 1999). Hospital Anxiety and Depression Scale Scores (Zigmond and Snaith, 1983) measured at the time of interview ranged between 1 and 20 with a mean of 11.3.

In the description of the interview results given below individual subjects are referred to by their unique identifier which has the format *letter00number*.

All subjects interviewed were happy to discuss all topics on the interview guide – none declined to discuss a particular topic, although occasionally some were less expansive when discussing their memory problems than other, more general topics. Subjects commonly used humour and none displayed evidence of frank emotional distress during their interview. In many cases there was evidence that subjects had limited recall regarding their experiences and reduced insight into their limitations: In a number of interviews there were inconsistencies either within the patient's own account or between their descriptions and those of the linked advocate. Subjects often freely admitted that they were unable to recall certain details, particularly those relating to the process of assessment at the memory clinic, for example:

Interviewer: And how did you find going to the memory clinic?

E001: Dare I say I can't remember (laughs)

Some subjects appeared to attempt to minimize their problems – be it consciously or subconsciously - when their accounts were compared with those of their linked advocates. Others demonstrated awareness that their insight into their limitations might be limited, for example:

U006: I feel that 90% of the time I'm as right as ninepence (laughs). That's how I feel. But, of course, I don't know how other pe', what other people are having to put up with, do I?

Several subjects appeared to attempt to 'cover up' their lack of recall by moving the discussion away from their own experiences onto a more general discussion, or by recounting anecdotes unrelated to the topic at hand.

The themes emerging from the interviews carried out by the two researchers (the author and CM) were very similar.

3.3.1.2 Challenges Presented by Mild Cognitive Impairment and Coping Strategies Developed

The vast majority of problems noticed by subjects as a result of MCI were related to recall. Most commonly this manifested as difficulties remembering recent events or conversations, the names of friends, future plans such as appointments and the location of items around the house. Several reported that problems with naming extended to objects and that their verbal fluency was affected by word finding difficulties. A number of subjects said that they had also developed difficulty with writing and reading comprehension. Some subjects described increasing difficulty with general activities of daily living, particularly managing personal paperwork and finances and some reported episodes of spatial disorientation and impaired driving skills. As a result a small number reported that they had become increasingly reliant on their spouse. Many subjects described the detrimental effect that their cognitive problems had had on their social lives and ability to continue with hobbies that they had previously enjoyed. A perceived change in personality, sometimes associated with decreased self-confidence, was reported by about half the subjects and a number reported feeling 'generally slowed down'.

A minority of subjects reported that, although they recognized that they had a memory problem, it had not had any significant impact on their daily life, for example:

Interviewer: And the problems that you've had with remembering, does it have much impact on your day-to-day life?

D007: That's a good question, that. No, I don't think it does. Because I keep a diary, and I write down all the people I have to go and see, and also the engagements I've got.

Given the age group of the subjects interviewed it is not surprising that a number reported having concurrent medical conditions, such as arthritis and cardiac failure, which adversely affected their quality of life. It was not uncommon for these subjects to report either being more concerned about, or more limited by, their physical health problems than the symptoms of their MCI, for example:

D003: Two or three of the things that really irritate me: Not being able to write a decent (sentence)... That's really the, umm...result of the TIA, because my hand hasn't got much by the way of delicacy about it.

A similar view was expressed by another subject who had physical limitations due to ill health:

E005: Both my hands are useless basically. Small things cannot be held. I've had operations, but not successful....and this is the thing that depresses me (gesturing to hands), not that (referring to memory problems).

Many subjects reported being aware that their memory problems had an impact on relationships with those around them – most commonly a negative impact on a relationship with a cohabiting spouse. The most frequently reported impact was frustration or irritation arising between the couple as a result of memory lapses, for example:

D002: The only problem I have is my dear wife, she gets so upset. And when I ask her to tell me something, instead of saying "Darling, it's so-and-so" she goes (in a loud voice) "It's so-and-so". And I (say) "Oh, tell me off then, see if I care".

Another interviewee remarked:

R001: I think sometimes it can be a bit exasperating for him, you know, if it's something like, some small arrangement we've made and, and you know, it's, I've forgotten it.

Several subjects reported being concerned about the distress that their condition caused their spouse, for example:

D003: And it's distressing to (my wife) when I can't remember when you're coming... or what plane our granddaughter's caught this morning and so on. It's everyday minutiae really, and

it, it does cause a certain amount of marital irritation. (whispers) (My wife's) dad had dementia, so she's very sensitive about that.

There was a roughly equal split between those subjects who reported openly discussing their memory problems with their spouses and those who said they did not. Subjects who did not discuss their difficulties with their spouse said that this was either because they felt there was no need to do so or because they found it difficult. A significant minority of subjects had not discussed the subject with other family members, such as their grown-up children, most often for fear of adding burden to what they perceived as their already very busy lives. Interestingly, in contrast to this, many subjects had discussed their memory problems with friends, saying either that they had no hesitation in doing so as they did not feel that their memory was much worse than their peers or that they valued the support that their friends were able to offer once they were made aware of their difficulties. For example:

Interviewer: And do you mind people knowing particularly?

D013: Not particularly. Because I think if they know and they see some of the loss I get into, if that's the best word, they don't bat an eyelid. Because they know that's what's happening, you know.

Interviewer: So it's reassuring to know that they understand why...

D013: They sometimes try to help me by telling me what we were talking about before.

Where subjects described strategies they had developed to cope with the challenges presented by their symptoms of MCI these almost exclusively related to the use of written reminders – either produced themselves, for example personal diaries, or by family members, for example reminder notes left around the house. About a third of subjects admitted to attempting to cover up their difficulties for fear of causing embarrassment, for example:

R002: Sometimes somebody comes up...and says "We haven't met for years have we? And how's (your wife)? How are things? Did you get on all right with that holiday?" I haven't the faintest idea who they are or what they're talking about. Of course, I have to pretend I do, don't I? (laughs) Otherwise she might think I was rude.

Some reported attempting to overcome their difficulties by greater 'mental effort', for example trying to pay more attention in an effort to retain information.

3.3.1.3 Feelings About Mild Cognitive Impairment

Perhaps unsurprisingly no subjects reported positive feeling about their memory problems.

The commonest negative emotions described were irritation and frustration, related to the effects subjects' symptoms had on the practicalities of daily life. For example:

K006: The problem that I have is I start doing one job, and then I change to another one, and I try to...do it but it's sometimes awful 'cos I can't do it and I get frustrated... 'cos I can't fix something or other.

Many subjects also described experiencing anxiety about their symptoms. One subject described her concerns about her memory difficulties:

R001: (There is a) certain amount of apprehension in case I've forgotten something really, really important, or maybe forgotten to meet a friend or something, but I haven't, I never have, but it's kind of at the back of my mind.

Feelings of sadness related to symptoms were also commonly described.

About half of those interviewed described feeling embarrassed by their difficulties or being concerned about the way other people would react to them. One subject said:

R008: I do miss my friends. And I'm trying to make contact with them now a bit more, and... But, you know, then I worry they'll come and they'll say, 'she's gone off her rocker,' you know.

Interestingly, many subjects used the negative labels they had expressed concerns about when referring to themselves in the course of the interviews, for example:

E009: I did say to my, one of the GPs (general practitioners) I went to, "I really do think I'm going round the bend"

Although negative emotions were common, a significant minority of subjects reported a neutral reaction to their symptoms. Where this was the case it was usually because either the subject felt that their memory changes were within normal limits for their age or that they had very little impact on their life, for example:

U002: I accept that I have something, it's not unusual and it's nothing to be ashamed of.

Again, emotions related to thoughts about the future were all either negative or neutral. The negative emotions reported were almost exclusively anxiety about the possibility that their memory might continue to deteriorate with time. About a quarter of the subjects interviewed

indicated (entirely unprompted) that they would consider euthanasia should they develop severe memory problems, for example:

E009: I don't want to be a nuisance, you know, anyone.....I'd rather, you know, just get out and I said to my GP, "I don't want any heroics, I mean, if it keeps you in a state when you can go on and exist but I don't want to be utterly miserable and depressed on someone else, you know and be a burden

In contrast, many subjects reported that they were not particularly concerned about what the future might bring, for example:

R002: I don't think too much on the future. I think my own view is that at my age it's best to live in the present. Because you can try and make provision for all the things that might happen, and you simply can't. There are so many contingencies that can possibly happen.

Many subjects' feelings about their symptoms seemed to be related to their experiences of others' memory problems. Those who reported being aware of others with 'mild' difficulties often stated that their symptoms were on a par with others of their age and that they were therefore not particularly concerned about them. Those who reported having experience of others with dementia were particularly likely to report being concerned that their symptoms might represent a serious problem. For example, one subject whose cousin and aunt had both had severe dementia said:

D013: Well the only shock was when my cousin, when I understood that he had Alzheimer's. And his mother...Just, it goes through the back of your mind is that is there any genes that are running around that would eventually end up...? I don't go around thinking about it all day long, but it goes through my mind at times.

3.3.1.4 Attributions

Subjects attributed their symptoms to quite a wide variety of causes. Most commonly they reported either being unsure about their origins or felt that they were part of the 'normal' ageing process. Some subjects held coexisting 'external' factors such as physical health problems, stress or fatigue responsible whilst others blamed 'internal' factors such as their personality or a lack of effort to maintain cognitive function.

Only a minority of subjects were aware of the term 'mild cognitive impairment' pertaining to their memory problems and those who used the term often indicated that they had gleaned it from the study information pack (which they often had to hand during the interviews). This may well have reflected lack of recall of the information given at clinic as all of the clinic

letters reviewed during the screening process explicitly stated that the diagnosis of MCI had been given to the subject and in most cases a discussion regarding its nature and implications had occurred. However, none of the subjects who had apparently learned the name of their diagnosis from the study information pack appeared distressed by this, most appearing to accept it as part of the diagnostic process. Most subjects who were aware of the term 'mild cognitive impairment' were unable to elaborate significantly on its meaning, for example:

Interviewer: So what's your understanding of that term, that mild cognitive impairment?

D003: Well, that is it. I don't remember what I used to remember. I have certain difficulties that I've already explained to you...

3.3.1.5 Current Sources of Information and Support

The vast majority of subjects reported having received little or no information from health professionals about their diagnosis. However, aside from a small number of subjects who were angry at the perceived lack of information offered, most were ambivalent about it and few had made efforts to look elsewhere for relevant information. For example,

Interviewer: When you went to clinic, and they said to you, 'well, there's nothing too bad,' was that enough information for you? Would you have wanted any more information about the results of the tests, or...?

K002: No, I felt all right. I was quite pleased.

Several subjects stated that they had not looked for information from other sources (such as the internet) as they did not wish to do so until they had received personal feedback about their diagnosis. These subjects reported that they wished to be certain that any information they accessed was relevant to their specific situation.

D008: I don't want to put myself into a, what 'I think', rather than what 'I know' I'm told that I've got, because I don't wanna type into the computer and it gives me out all these anxiety lists of things 'Oh, you've got this, you look that way'. I don't want any of that, you know. I just want, if you tell me that I've got X, Y, Z, then that's what I'm gonna focus on, but I don't have an open mind to what I haven't got....To 'think' is one thing, but to 'know' is the best thing, and that's what I want.

Given the fact that many of the subjects interviewed had difficulty recalling the details of the assessment process it is difficult to know whether subjects were genuinely given little

information about their diagnosis or were simply unable to remember being given it. As noted above the clinic letters for these subjects recorded the fact that the diagnosis had been given in clinic and that, in many cases, a discussion about the diagnosis had occurred. However, many of the subject reports on this subject did correlate with those of their linked advocate suggesting that, in some cases at least, subject reports were probably accurate. An alternative explanation is that advocates also had poor recall of information given at the clinic appointment. For example, when asked about the information they were given at the clinic appointment these linked subjects and advocates, who were interviewed separately, stated:

Interviewer: And what information did they give you at the end of that appointment?

D003 (PWMCI): Nothing.

And:

Interviewer: aside from the information that I've sent out to you, what other feedback did you have after all these assessments?

D006 (advocate of D003): Nothing, not a thing

This experience was also reported by others:

Interviewer: And what did they tell you at the end of that assessment process?

U002 (PWMCI): (pause) I can't remember exactly. Um, I mean just say yes, you do have a memory problem but I can't say I was given any tips or information.

And:

Interviewer: So, what other information did they give you?

U003 (advocate of U002): Not a lot really.

Where subjects did report receiving information about MCI roughly equal numbers reported having obtained it from healthcare professionals and from the media.

The most commonly reported sources of support were subjects' spouses and friends. Subjects most often described their spouses acting as a 'back-up' to jog their memories when necessary. For example:

D007: If I want to ask a question about recent work, I ask my wife, and she'll tell me what I want to know.

Where subjects described receiving support from friends within the community this was often a mixture of the practical and the emotional, for example:

D012: I've got nothing to hide from (my friend) no. She's been to the hospital with me when I used to go for different various things, yeah.

Other relatively frequently reported sources of support were church groups, other family members (aside from spouses) and formal services provided by health and social care.

3.3.1.6 Experiences of Health Services

Most subjects reported either positive or neutral experiences of consulting their GP about their memory problems. Those who reported positive experiences generally reported a good relationship with their GP and being pleased that they had been referred promptly to secondary care. For the few subjects who reported negative experiences this was most commonly because they felt that their memory complaints had initially been dismissed as part of 'normal ageing' rather than properly investigated. Subjects described various reasons for their initial presentation to the GP, roughly equally divided between having instigated the consultation themselves, having been prompted to do so by others (usually a family member) or having reported a memory problem during a consultation about a coexisting physical health problem. For example, when discussing this topic a subject who had instigated the initial GP consultation himself said:

E005: But I noticed that things weren't quite right. And in view of my experience with the medical profession with these (referring to neuropathy affecting hands), I immediately went to the doctor, who immediately got me to (the memory clinic at the hospital).

When asked why she had consulted her GP, a subject who had been prompted to do so by her son and daughter-in-law, said:

E001: I think it was because of the family.

Interviewer: Okay. And what concerns did they have?

E001: (short pause) Concerns that I was forgetting and perhaps not eating properly and, um, err forgetting appointments.

A subject who had reported their memory problems during a consultation about another health matter said:

E007: I was seeing the GP anyway, and I said, 'another thing I wanted to ask you about is this memory situation, not remembering to do... Well, is there anything I can do about it?'

The reports of experiences at memory clinics (and analogous services) were more varied. Some subjects had a generally positive opinion of the memory service, particularly of how well it was run and how pleasant the staff had been. Quite a number of subjects reported feeling relieved that the assessments hadn't identified a more serious memory problem, for example:

K002: I'm glad, I'm glad I went now, because I realize that I am like all... We're all the same, and it's not dramatic.

Many subjects, however, were left with negative impressions of the memory service they had attended. The most common complaints were focused on the assessment process, particularly cognitive testing and neuroimaging. Many subjects reported finding this process unpleasant - either because it seemed too lengthy or difficult or because they felt it did not seem appropriate to their symptoms. For example, one subject said of his experience of cognitive testing:

K002: I felt daft, yeah. It made me... Oh, I thought, don't want all this

Another common cause for complaint was the perceived lack of feedback following the assessment: many subjects reported feeling they had not been given a diagnosis or had received insufficient information about their condition or potential treatment options:

D008: I'm going through a sort of ping-pong, because I've been sent here, sent to (Hospital A) for MRI scans – never seen the results of those, over, over a month ago – and I've got this other appointment in a clinic in (Hospital B). So I, you know, in my head, no-one's told me a single thing about this since I started, you know. And I go to the doctor, no idea. No idea where the results are going to.

Negative impressions of memory services were also caused by practical issues such as lengthy waiting times for follow-up appointments and difficulty with hospital parking.

While many subjects did have strong positive or negative feelings about their experiences within memory services roughly an equal number felt ambivalent about them.

3.3.1.7 Suggested Improvements to Services

CHANGES TO SERVICES

Many of the subjects, when questioned, could not think of any specific changes they would like to see made to memory services – which was in keeping with the ambivalence many displayed about their experiences. The vast majority who reported not wanting any particular changes to services stated that they felt they simply didn't need any additional information or support at the current time, for example:

Interviewer: And is there any other support that you think would have been useful for them to suggest to you from clinic, anything particularly around memory, or not really?

E007: No, I don't think anything's ever been suggested. Any help that might help in that direction at all. No.

Interviewer: Okay. And there's nothing that you wish you could access?

E007: I don't honestly think so.

In accordance with this view very few subjects had searched for information on available support independently, for example at public libraries or on the internet.

Some subjects reported that, although they felt that that their experiences within memory clinics were imperfect they were unable to suggest improvements as they felt that alternative assessment processes or the information or support they really wanted just didn't exist at the current time, for example:

E005: If there was any, any material that could have been given to me to improve the situation, then I would have liked to have heard about that. But I don't think there is.

Where changes were suggested these fell into two main categories: those relating to the process of assessment and those relating to the interaction with memory service staff. Several subjects reported that they would have liked to have been assessed using tests which appeared more appropriate for their cognitive complaints, for example:

Interviewer: Do you think if they'd used a different assessment, more difficult questions, that might have changed things?

E007: Yeah, I think it might... But I mean the questions, as I explained to you, were so very simple that I didn't really think they were testing my memory at all.

Subjects who suggested possible improvements to interactions with staff reported varied concerns such as feeling they needed more time in clinic and wanting more reassurance and support.

INFORMATION PROVISION

Where subjects did make a suggestion about improving experiences of healthcare this was most commonly that more information should be provided. Subjects reported wanting information on a variety of topics, the most common of which were:

Strategies to cope with existing symptoms

Many respondents said that 'hints' and tips' about how best to deal with their limitations would be helpful, for example:

R001: Maybe there would be, could be hints of how to, get round it, you know. Yes, I would quite appreciate that.

How to prevent further deterioration in memory

Quite a number of subjects stated that they would be interested in information about what they could do to preserve their cognitive function, for example:

D008: If that's what I've got then what is the help or, you know, how can I help myself or what is the way, the way forward with it, you know? Does it, you know, if it means sort of a, a digestion of drugs?

Feedback of the results of their assessment

Some subjects were particularly interested in receiving details of the results of the tests which they had undergone at memory clinic, both cognitive tests and other investigations such as imaging. For example:

D007: I suppose an assessment from the hospital would have, would have helped as well, from, the doctor there. But he didn't tell me a lot at the end.

Treatment options

Many interviewees expressed an interest in receiving information about potential therapeutic options (both pharmacological and non-pharmacological) for their cognitive problems, for example:

R001: if there was a cure I'd love to know about it (short laugh)

Other topics that subjects reported wanting information about included their likely prognosis and common causes of cognitive impairment.

Many subjects did not have particularly strong preferences about how information should be provided but there was a general consensus that face-to-face feedback of individual assessment results combined with provision of general written information would be the most helpful.

3.3.2 Descriptive Results of Advocate Interviews

3.3.2.1 General Description of Interviews

In total 20 semi-structured interviews were carried out with advocates, 17 of these were conducted by the author and 3 by another researcher (CM). 15 of the advocate interviews were carried out with the subject alone and 5 in the presence of the linked PWMCI. Interview durations ranged from 16 minutes to 1 hour and 8 minutes, with a mean of 31 minutes. The age of the subjects interviewed ranged from 42 to 84 years with a mean of 69 years. Eighteen of the interviewees were female and 2 were male, all were of White British Origin. Thirteen of the advocates were spouses of the PWMCI, 2 were offspring, 3 were other family members and 2 were friends.

For the most part advocates were willing to discuss the subjects on the topic guide openly. In two cases advocates (both spouses of PWMCI) became distressed during the interview but, despite being offered the opportunity to terminate or pause the discussion both wished to continue. Indeed, one stated at the end of the interview how helpful it had been having someone to talk to about their experiences. Occasionally advocates appeared reticent to discuss a particular issue, for example their thoughts on the future; this manifested as either very brief answers on the topic or the advocate steering the conversation away from the original question. The majority of advocates were spouses of PWMCI and therefore had, for the most part, accompanied PWMCI during their contact with healthcare services and had a good insight into the day to day challenges posed by the PWMCI's cognitive problems. Amongst non-spousal advocates the degree of contact with the PWMCI, and hence awareness of their difficulties and experiences of healthcare services, was more varied.

The themes emerging from the interviews carried out by the two researchers (the author and CM) were very similar.

3.3.2.2 Challenges Presented by Mild Cognitive Impairment and Coping Strategies Developed

Advocates reported a very wide range of difficulties which they attributed to the PWMCI's cognitive problems. Foremost amongst these were challenges caused by impairments of the PWMCI's short to medium term memory for a variety of things including recent events and conversations, arrangements that had been made and the names of acquaintances. One advocate said of his wife:

R003: I mean, you know, (we) sort of discuss what we're going to buy in the shops, and then, you know, she'll get to the shops and she's totally forgotten...

Another change very commonly reported by advocates was PWMCI having increasing difficulty managing paperwork and finances, for example an advocate, referring to her husband, said:

D006: If he hasn't got anything to do, he will start going through the filing cabinet. Months ago he came out, he said "Look, we've got more in the bank than we thought." And I looked at it, and I looked at the date of the statement. I said "This is at least two years old."

About half of those interviewed reported noticing a change in the PWMCI's personality with a variety of manifestations including increased anxiety or irritability, low mood and decreased self-confidence. Speaking of her husband one advocate said:

U007: He's always been one that's had a bit of a short fuse about things. But never with me. And since he's had this, he is sometimes quite nasty.

Many advocates reported that the PWMCI's social interactions and ability to continue with previous hobbies had been affected by their cognitive problems. Most commonly they described the PWMCI finding that their cognitive problems made it difficult for them to socialise, particularly in large groups and that they had consequently become more isolated. Describing her relative, one advocate said:

K007: I've tried to encourage him to go to social occasions... but I've noticed that where he used to love coming to our house, and he would engage with us, if there's anyone else there, he'll actually remove himself, and he will go and sit in another room.

Other, relatively frequently described, changes included episodes of spatial disorientation, interruptions to family plans such as holidays and verbal problems such as word finding difficulties.

As in the interviewees with PWMCI, who frequently mentioned co-existing medical conditions, the advocates often referred to either their own health problems or those of the PWMCI. Several advocates described finding it difficult to be certain whether many of the problems they described were caused by the PWMCI's physical or cognitive problems – or indeed whether the cognitive problems were caused by physical ill health in the first place. For example, describing the onset of his wife's memory problems this advocate said:

R003: ..whether, whether the minor stroke actually caused it, or whether they just happened at the same sort of time, is, I mean....not at all clear

In an interesting contrast to the subjects with MCI , where advocates referred to their own health it was most commonly their mental health that they talked about – either in terms of emotional burden or, more frequently, concerns about their *own* memory deteriorating.

Unsurprisingly, given the myriad of problems advocates described many reported these problems had had an impact on their relationship with the PWMCI, particularly in causing increased arguments. This advocate said of her husband:

U007: I mean, some days it is very difficult. I mean I have a... we've had sort of several little... we've never really argued much. In fact all the years we've been married. I think we've had more arguments this last year than we've ever had.

There was a roughly equal split between those who felt able to discuss the PWMCI's cognitive problems with them openly and those who did not. One advocate said of attempting to initiate a discussion with her relative about her memory problems:

E002: I don't know if she'd like to talk. We've tried to give her the openings once or twice, but she hasn't taken them. Like: "It must be quite worrying to people" she's a bit sort of "Well it happens to old people doesn't it?" sort of... And you feel well if that's her choice, I don't feel able to push any harder.

Whereas another, referring to her husband said:

U003: (My husband) and I talked about it, very open about it, and we sort of said well, as we get older, something's going to go on in life, you know, we just said well it looks as if this might be your lot, you know, but we're all in it together, so we talked about it openly and realised, yes, there was a problem

There was also an equal split between those who were able to discuss their situation with other family members and friends and those who did not. Advocates reported a variety of reasons for not being open with others including the subject never seeming to come up in conversation and a reluctance to burden others with their problems. This advocate said of discussing her husband's memory problems with their grown up children:

R004: it seems hardly fair to ring them up at nine o'clock in the evening and say "By the way, about this memory problem..." And when we see them, it's not always possible to discuss private matters like this.

Overall, many advocates described a feeling of watching the person they had known changing significantly in a number of ways, often associated with a degree of 'loss'. A minority, however, said that they had not noticed that the PWMCI's cognitive problems had had any impact on their life.

Advocates also described a range of new responsibilities that they felt they had been obliged to take on as a result of the PWMCI's cognitive problems. These responsibilities tended to reflect the practical areas where PWMCI had developed limitations and hence the most commonly mentioned were taking over the organisation of household administration and finances and providing a greater level of general supervision to PWMCI on a day to day basis.

Some advocates described strategies which they had adopted to try to cope with the difficulties caused by the PWMCI's condition. Most commonly these involved practical approaches such as the use of written reminders or physical adaptations to make things easier around the house. A few advocates talked about the importance of maintaining some time for themselves in order to have a short break. For example, this advocate had developed a routine which involved the PWMCI (her husband) having a short afternoon nap, she said:

D006: It gives me a break. It sort of relieves the pressure. That sounds awful – we've been married fifty-seven years this year. But it is stressful. And I'm so thankful I instigated that, because I don't think I'd cope otherwise.

Several described attempting to 'prompt' the PWMCI's memory by trying to let them remember things by themselves, although those who used this approach were often unsure whether it was the right thing to do. One advocate described trying to prompt her husband's memory thus:

D005: Whether I should be telling him things or whether I should leave it and let him try and remember on his own? I mean, sometimes he says to me all of a sudden something, "I know what it is." I said, "Well think about it, just think for a little while and then I'll...." If I know what it is I'll tell him a bit later on but even that doesn't seem to work sometimes.

3.3.2.3 Feelings About Mild Cognitive Impairment

Whilst a few advocates described neutral feelings about the PWMCI's cognitive problems the overwhelming majority reported negative emotions. The most commonly reported reaction was sadness, for example this advocate said of her mother:

R0011: .. in the last few months, I went through a period where I got quite upset about it. Not hugely, but you know, I did a bit of sort of mourning. Just sort of saying to my husband that "You know, you don't realise that she used to be like me. You never saw her like that, but she was."

Advocates also commonly reported feelings of anger and frustration, either related to changes they had observed in the advocate or due to difficulties in accessing services. Describing his reaction to his wife's memory problems, this advocate said:

R003: Well, I think she does realize how frustrating I find it sometimes... I mean it's, it is sort of, I have to sort of pull myself together and say, say to myself, you know, that it's not her fault. She's not just being awkward

Anxiety and feelings of increased stress were also commonly reported, for example this advocate described her reaction when she first realised that her husband had a problem with his memory:

E006: It was the fact that he, he had forgotten that his relative had died. And we'd been to the funeral. And my heart... I can remember my heart just going, dropping, you know. Oh my god.

In several cases interviewees reported a discrepancy between the level of anxiety about the PWMCI's problems displayed by the PWMCI and their linked advocate. Where discrepancies existed there was a roughly equal split between cases where the advocate was the more concerned about the PWMCI's problems and vice versa. For example, this advocate said of her friend:

R007: Well, more recently, I mean she's been complaining for some years that she was losing her marbles. And I thought. 'Well, (PWMCI's name), you're so far up there I can't notice it yet.

Advocates' feelings about what the future might hold in light of the PWMCI's cognitive problems were also mostly negative. Many advocates reported anxiety about the future –

particularly regarding the possibility that the PWMCI might develop dementia or about their ability to cope with any further deterioration. This advocate said of her husband:

U007: But I do think, I think what might make it difficult that I can't cope with it, because sometimes when he gets like this, he does get very aggressive. And I think erm, if there's no aggression, I think I'd be able to cope with it. But I think if there was aggression, I would have trouble coping with it, you know.

Others reported uncertainty about the future: this advocate, the wife of a PWMCI, said:

U003: And I mean does the sort of memory loss that (my husband) has, does it necessarily lead on to all those terrible things, is, you know..?(You) cross each bridge, don't you, no point in preparing myself (short laugh) for something that might not come.

Quite a number of advocates reported having had experiences of other friends or relatives with significant cognitive problems such as dementia. In many cases these experiences appeared to influence their reactions to the PWMCI's difficulties – particularly in causing increased concern about the PWMCI developing more serious problems in the future. This advocate described her experiences of dementia in a family member and how it influenced her perceptions of her husband's early memory problems as follows:

D008 to put into context, his sister had I don't know how many years ..of virtually very, very bad dementia. But there was a few triggers that happened many, many years prior to this that we didn't pick up on at the time. And sadly my husband found that there was a couple of incidents where he did the same thing.

In contrast, however, some advocates reported experiences of dementia in other friends and family but either did not equate them with the advocate's problems at all or felt very certain that they were a completely different entity. This advocate, who had experience of several friends with dementia, said of her friend (the PWMCI's) cognitive problems:

R007: I have had quite a number of friends who have had Alzheimer's or cardiovascular dementia and so on. But it was, I could see that it was a very, totally, totally different thing...

Although a few advocates mentioned noticing mild cognitive problems in their contemporaries none reported being aware of others with a specific diagnosis of MCI.

3.3.2.4 Attributions

There were quite a variety of causes to which advocates attributed the problems they had noticed in the PWMCI. The commonest of these were changes which they perceived as 'normal' for their age group. One advocate said of her husband:

R004: He doesn't remember things that I would expect, events usually that I would expect him to remember. But then I don't sometimes either, so some of this must be ageing

PWMCI's physical health problems were also commonly blamed for contributing to their cognitive problems, at least in part. This advocate described her cousin's physical and memory problems thus:

K004: She's had other issues, which are gradually getting put right. And when I say from head to toe, that is literally from head to toe.

Interviewer: So other physical health problems?

K004: Yeah. Which we gradually getting sorted. You know, and did wonder whether some of those didn't help either.

Quite a few advocates referred to MCI by name or described the PWMCI's problems as something that was 'not dementia'. This advocate described the information they were given following her husband's appointment with a memory service:

Interviewer: And did they give you any feedback at the end of the appointment?

K005: Really just this mild cognitive thing. And they said it wasn't Alzheimer's, it wasn't dementia, which was phew, huge, huge...

Some advocates attributed the changes they had noticed to aspects at least partially under the PWMCI's control, such as their personality or the amount of effort they put into remembering things. For example, this advocate said of her husband:

K005: It's... how much is memory, how much is concentration is very difficult to tell. Because it depends a lot on how interested he is in a subject or whatever

3.3.2.5 Current Sources of Information and Support

When asked about sources from which they had obtained information about MCI many advocates said they simply had not received any. In the words of this advocate:

D006: Information – there's been a dearth of it, none

Where information had been obtained the commonest reported source was from written material and the internet; roughly equal numbers also reported receiving information directly from healthcare professionals (including what they had gleaned during the assessment process) and friends or family members.

The most common sources of support reported by advocates were friends and social groups (e.g. local church communities) and family members, including, in some cases, the PWMCI. This advocate, whose husband had cognitive problems, said:

U007: Yeah, I've got two good friends, that when I'm feeling really, wanting a good rant, I can go and have a good rant to them. And they listen very ni', you know. And that, it does make a great difference. 'Cos sometimes you just got to let it out. And once I've let it out, then I can sort of calm back down and then I can carry on then.

However quite a number of advocates (about the same number who reported receiving support from friends and family) said they did not receive any support

3.3.2.6 Experiences of Health Services

Many advocates had been involved to some degree in the PWMCI's assessment by their GP and the majority of them reported that there were at least some negative aspects to the encounter. A common reason given for negative experiences was the GP not appearing to pay sufficient attention to the problems reported by the PWMCI or advocate. One advocate said of her and her husband's experience of consulting his GP about his memory problems:

K005: Well it was, he just sort of totally blanked me. And was talking to (my husband). And I sort of, although I don't like to, I interjected and say "Well I think you know, his specialist at the hospital said he should be checked." "Well okay then, I'll get you an appointment." It took that, which I'd rather, I think that with older people and the fact that they can do things now, that if somebody is going, the GP should be picking this up.

Another common concern was a perceived lack of confidentiality: several advocates reported feeling uncomfortable 'reporting' on the PWMCI in their presence because they had been unable to discuss their concerns with the PWMCI's GP in confidence. This advocate said:

D006: As a result of my concern, we both went to see the doctor together. And it's very difficult to talk about your husband in front of him, very difficult. Because he said "I can only speak to you together." So we went to see him together.

Where advocates reported positive experiences of the GP assessment this was usually due to feeling that the GP took their (or the PWMCI's) concerns seriously or a perception that they acted quickly in making a referral to secondary care.

Advocates most commonly reported that the PWMCI had consulted their GP about their cognitive problems after prompting by themselves or another family member and in quite a number of cases the PWMCI had visited the GP about another matter and mentioned their concerns at that appointment. It was rare for advocates to report that the PWMCI had sought help from the GP regarding their cognitive problems spontaneously.

Most advocates had also been involved in the process of assessment at memory clinic and again negative experiences at memory clinics were common. The most frequent cause for complaint was related to the assessments used by the clinic; in many cases advocates reported that the process of assessment was unpleasant for them and / or the PWMCI. Many felt that the assessments used were not appropriate for the PWMCI's mild degree of cognitive problems, for example this advocate described the assessments she took part in at the clinic as follows:

D011: the questions I was being asked, you know "Did he get aggressive? Did he hit me? Did he do this, did he do that". It was all proform'. Yes it might be applicable to some people but it was totally un-applicable (to me).

Another common cause for complaint was a perceived lack of information about the diagnosis and treatment or support options – including, in some cases, feeling that the PWMCI had not actually received a diagnosis following the (often quite extensive) assessments. In a similar vein a number of advocates reported that they felt the communication from memory clinic had been poor. One advocate said of her experiences of the memory clinic which her husband attended:

U007: Yeah, the communication has been really poor, really. Which does make you feel, in my position, I don't know how he feels, but in my position, you feel a bit well they've told me that and they're just letting me get on with it, in a way.

Advocates also commonly described dissatisfaction with the set-up of the memory service, for example feeling that the gap between appointments was too long or disappointment at the PWMCI not being offered a follow up appointment. This advocate said of her mother being discharged from the memory clinic:

R011: What is quite difficult to take was that it was like “Yeah, there's a problem, it's not that bad. Off you go.”

Some advocates reported that they felt the service they were offered by the memory clinic was limited by financial constraints within the NHS.

However, in addition to the reports of negative experiences at memory clinics many advocates reported not feeling particularly strongly one way or the other about the clinic assessment process, indicating that they found it straightforward and satisfactory. A not insignificant minority also reported positive experiences – most commonly relating to the practical aspects of the memory service such as pleasant staff or an efficiently run clinic. This advocate said of the memory clinic her husband attended:

R004: Well the whole establishment, you know, I mean it's so careful, it's like NHS used to be. And nothing is too much trouble and it's excellent.

3.3.2.7 Suggested Improvements to Services

The majority of advocates felt that services could be improved. The most frequent suggestion was the provision of more information, particularly regarding likely prognosis, treatment options and what they themselves could do for the PWMCI. When asked what additional information she would have liked to have received regarding her husband's cognitive problems, this advocate said:

D007: Well, what help can be given. And I mean, can I do more, can I sort of... somebody said (I) should make (him) tell me exactly what we did yesterday sort of thing. I mean, would that help? This is the sort of thing, if I know what I can do...

About half of those who wanted extra information stated a preference for this being given face to face from a healthcare professional and half preferred a written format.

Another common request was for the provision of more support for the PWMCI and / or themselves, or at least some information on the sources of such support. Areas that advocates mentioned being interested in were support groups for themselves or the PWMCI, psychological support and practical services such as 'home help'.

Several advocates suggested changes to the practical aspects of the assessment process including the type of assessments used and whether the advocate and PWMCI were interviewed together or separately. This advocate, who was asked to give collateral history

during her husband's memory assessment in his presence, when asked by the interviewer whether she would have preferred to talk to the doctor in confidence, said:

U007: I think actually it would have been quite helpful. Because I wouldn't, there were some things... I mean, I'm saying things to you that I wouldn't say if he was here. Because I think it would be quite sort of hurtful to say them. So I think it could have been. He did give me, I did go outside and have a sort of a questionnaire to fill in. But that wasn't all that big, and it was a very broad spectrum really. Not exactly what... no, it would have been easier I think if I could have put my four penn'orth in as it were, you know.

On the other hand some of the advocates whose assessments took place separately from the PWMCI reported that they would have preferred to have remained with the PWMCI during the process, for example this advocate who saw the doctor separately from her husband said:

E008: I realise that they wouldn't know whether he was giving the right answers, so if I could have been there to just indicate whether what he was saying was correct....

In keeping with the reports of poor communication from the memory clinic several advocates suggested that their experiences could have been greatly improved by better communication from the clinic – both in terms of sensitive discussions about diagnosis and regarding practical matters such as the timing of follow up appointments.

Some advocates felt that there wasn't much scope to improve services. This group generally fell into two categories: those who felt that they didn't need any extra information or support at the current time and those who, despite reporting unsatisfactory experiences, couldn't see how changes to services would improve matters. In the latter group many advocates reported feeling that the information they really wanted, such as how the PWMCI's cognition would change over time, just wasn't possible to provide.

When asked about whether she would wish to attend a support group one advocate said:

D016: No, not really my cup of tea, no. Not at the moment. I mean, I think if he was... please God not, but if he did get worse.. maybe I would then.

This advocate, who reported that her relative had become quite distressed by the assessment process, said:

K007: But the doctor was very good. I mean he said “Now, come on, take your time.” It wasn't that he was aggressive. And I don't really know how else you would do the questioning.

3.4 Discussion of Interview Results

3.4.1 General Comments

Interviews with people with mild cognitive impairment (PWMCI) and advocates were undertaken in order to document the experience of living with mild cognitive impairment (MCI) from the perspectives of those living with the effects of the condition. Interviewing continued until data saturation was reached i.e. no new substantive themes were revealed by further interviews. This occurred after 23 interviews with PWMCI and 20 advocate interviews – approximately the number that it was hypothesised would be required.

There were no significant difficulties with the conduct of the interviews. Although it was planned that, ideally, PWMCI and advocates should be interviewed separately, there were several cases where subjects expressed a wish to be interviewed together, usually stating that they wished to make sure that all information was discussed with both parties. There is a possibility that this influenced the content of these interviews, particularly in the topic areas that may have been difficult to discuss in the presence of the study partner, such as relationship difficulties. However, the themes apparent in these interviews were not substantially different from those in interviews where the subjects were interviewed separately.

The mean duration of interviews with both PWMCI and advocates was just over half an hour. There were a few very short interviews; interviews with PWMCI were often short where they had particularly poor recall regarding their experiences and advocate interviews tended to be short if they were a friend of the PWMCI (rather than a family member) or had minimal concerns regarding the PWMCI's cognition. Despite recruiting for the study in a wide variety of both urban and rural areas in the south of England, the subjects were all of white British origin which meant that no information regarding issues which might be of particular concern to ethnic minorities was obtained. At 78 years the mean age of PWMCI in the study reflected the older age of most PWMCI in the community. The lower mean age of advocates (69 years) reflected the fact that, while over half were spouses of PWMCI, a significant minority were offspring or other younger relatives. Interestingly all but two of the advocates interviewed were female despite the fact that there was a roughly equal split between male and female PWMCI. This was mostly due to the fact that, where the advocate was non-spousal (i.e. another type of relative or friend) they were usually female – in keeping with the fact that informal carers in the general population are more commonly female (The NHS Information Centre, 2010).

Recruitment to the study was designed in such a way that it should reflect the diversity of patients seen in memory clinics. Consequently, it was not mandatory for participants to fulfil the Petersen diagnostic criteria for MCI. However, it was encouraging to note that the majority of the PWMCI interviewed (N = 16) did, in fact, meet the criteria meaning that the study population, as well as reflecting the diversity of memory clinic patients, was comparable to many of the populations studied in previous research in this area. The mean Mini-Mental State Examination score (MMSE) (Folstein et al., 1975) (for those PWMCI for whom it was available) was 26.9. The MMSE score has poor sensitivity for identifying MCI and is therefore not an ideal screening tool; however it was used as an approximate marker of general cognition in this study as it was the cognitive test which was most commonly performed across all study sites and therefore the greatest number of subjects had scores available for this test. The MMSE has been shown to have a fairly good sensitivity (86%) for identifying dementia when used as a screening tool with a cut-off of 25 (McDowell et al., 1997) or 26 (Kuslansky et al., 2004). The fact that the mean MMSE score for our subjects was above these values provides some reassurance that these subjects were unlikely to have a diagnosis of dementia. The mean Hospital Anxiety and Depression Scale (HADS) score (Zigmond and Snaith, 1983) for the MCI group was 11.3 which corresponds to 'moderate symptoms of anxiety / depression'. This is in keeping with the known association between MCI and neuropsychiatric symptoms (NPS) (Lyketsos et al., 2002, Feldman et al., 2004).

Although the themes identified in the interviews with the PWMCI and their advocates were broadly similar there were several areas where disparity was evident – both between the accounts of individual linked PWMCI/advocate dyads and in the overall analysis of responses from the MCI and advocate groups. One reason for this, as noted in the 'Descriptive Results of Interviews with People with Mild Cognitive Impairment' section, appears to be the fact that many of the subjects clearly had limited recall of their experiences and insight into the challenges resulting from their cognitive problems, a phenomenon which has been reported in other studies (Vogel et al., 2004, Frank et al., 2006a). Another likely reason is that many of the advocates interviewed were beginning to take on caring roles and experiencing the psychological and practical burdens associated with this, further widening the gap between themselves and the PWMCI – especially where the PWMCI's impaired insight resulted in minimal concern about their own condition. Several advocates described being in a situation where they were 'falling between two stools': neither being in the situation of caring for someone with dementia who lacks decision making capacity and therefore feeling 'entitled' to take on that role, nor being a carer for someone with a physical disability who retains full cognitive capabilities and therefore does not require advocacy in

decision making. Rather, many advocates described feeling that they had a key role to play as an 'intermediary' in the PWMCI's care without necessarily having any official recognition of this. This reflects the rather unique role of the advocate in MCI and is in keeping with the difficulty we had in finding a suitable term to describe this group – who would be labeled as 'caregivers' if the person were to have dementia – but for whom a suitable term does not seem to exist at present.

3.4.2 Challenges Presented by Mild Cognitive Impairment and Coping Strategies

The challenges described by PWMCI were similar to those that have previously been reported in comparable studies and were in keeping with the cognitive deficits known to occur in MCI (Albert et al., 2011, Joosten-Weyn Banningh et al., 2008, Frank et al., 2006b, Lu et al., 2007a): e.g. problems with recall of recent events relate to deficits of episodic memory, problems with naming, verbal fluency and comprehension relate to language deficits, difficulties managing paperwork and finances relate to executive dysfunction or attention deficits and spatial disorientation relates to visuospatial deficits. Advocates' descriptions of the challenges faced by PWMCI were broadly similar to the PWMCI's descriptions and both groups reported consequent effects on the PWMCI's day to day lives, for example limitations in completing instrumental activities of daily living (IADLs), socializing with their peers and negative effects on family relationships. These findings were once again in keeping with those of other similar studies (Adams, 2006, Frank et al., 2006b, Lu and Haase, 2009, Blieszner and Roberto, 2010, Blieszner et al., 2007, Kuo and Shyu, 2010, Garand et al., 2007, McIlvane et al., 2008)

New responsibilities reported by advocates reflected the deficits PWMCI had developed (as described above) and were similar to the 'carer burdens' described in previous studies of this topic (Joosten-Weyn Banningh et al., 2008, Beard and Neary, 2012, Adams, 2006, Frank et al., 2006b, Lu and Haase, 2009). Coping strategies described by both PWMCI and advocates were overwhelmingly practical (or 'problem focused') in nature, for example the use of written reminders. One significant exception to this was the advocates who had developed a policy of maintaining some free time for themselves to allow a rest from their 'caring' responsibilities reflecting a combination of problem and emotion focused approaches to coping. Many previous studies have found that roughly equal proportions of carers of PWMCI use problem-focused and emotion-focused coping strategies (Lu et al., 2007a, McIlvane et al., 2008, Beard and Neary, 2012, Roberto et al., 2011, Lu and Haase, 2009, Blieszner et al., 2007), hence the emphasis on problem-focused coping identified in this study was in contrast to previous findings.

3.4.3 Emotional Consequences of Mild Cognitive Impairment

PWMCI and advocates described a range of negative emotional responses to the PWMCI's cognitive problems and regarding the future, again in keeping with previous work in this area (Joosten-Weyn Banningh et al., 2008, Lu et al., 2007a, De Vriendt et al., 2012, Adams, 2006, Frank et al., 2006b, Lu and Haase, 2009, Blieszner et al., 2007, Kuo and Shyu, 2010, Roberts and Clare, 2012). In a number of cases there was a discrepancy between the emotions expressed by PWMCI about their condition and those expressed by their linked advocate: Whilst advocates described almost exclusively negative emotions quite a number of the PWMCI reported neutral feelings about their difficulties, often stating that they felt that they were within normal limits for someone of their age. This discrepancy was commented on by a few subjects who stated that the advocate was much more concerned about the PWMCI's problems than they themselves seemed to be – but it was also apparent in quite a number of the PWMCI-advocate dyads, even when not explicitly mentioned. Explanations for this inconsistency include the limited insight and / or recall exhibited by some PWMCI and the emotional and practical burdens described by some advocates which affected them but not the linked PWMCI. Previous studies have confirmed that, in people with cognitive impairment (including MCI) who have reduced insight, measures of self-rated quality of life are less reliable than in those in whom insight is preserved (Berwig et al., 2009, Ready et al., 2006). The challenges of measuring insight and the potential effect that decreased insight might have on patient reported outcome measures (PROMs) in MCI were also discussed in a recent review by Frank *et al.* (Frank et al., 2011). They commented on the fact that most measures of insight in MCI rely on informant reports as a 'gold standard' – with discrepancy between reports from the PWMCI and the informant indicating decreased insight on the part of the PWMCI. However they argue that, where the informant is a caregiver (as in this study) the accuracy of their report may be affected by factors such as their own health, level of burden and presence of NPS and therefore discrepancies in reporting may not always be attributable to decreased insight on the part of the PWMCI. Many advocates in our study did indeed express concern about their *own* mental health – sometimes creating an interesting contrast to a linked PWMCI who had expressed minimal concern about their diagnosis. A further possible explanation for the discrepancy in the emotional reactions of PWMCI and advocates is the phenomenon described by Roberts and Clare whereby, despite high level 'meta-representational' awareness of cognitive difficulties being intact in the PWMCI they studied, the *expression* of this awareness was influenced (and reduced) by various psychological and social factors (Roberts and Clare, 2012).

In a small number of cases the PWMCI in our study reported *greater* concern about their condition than their linked advocates. Frank et al. also commented on this phenomenon -

pointing out that PWMCI may become aware of deficits before they are detectable by others resulting in an apparent 'overestimation' of deficits as rated by subject reports compared to those of informants (Frank et al., 2011) – and it has also been noted in some other studies and a review of insight in PWMCI (Farias et al., 2005, Tabert et al., 2002, Roberts et al., 2009).

Many subjects reported having had experiences of others with memory problems and these often appeared to influence their feelings about the PWMCI's current difficulties. This was particularly the case for those who had 'first-hand' experience of family members or close friends with dementia: this group was more likely to express anxiety about their symptoms potentially representing a serious condition, an association also identified in Lingler et al's and Robert and Clare's studies (Roberts and Clare, 2012, Lingler et al., 2006). However, this is in contrast to Beard and Neary's findings that participants in their study of experiences of MCI vehemently denied any association between their experiences and Alzheimer's disease (AD) (Beard and Neary, 2012). The participants in that study reported that they felt their awareness of their deficits was what distinguished their condition from AD. It is also in contrast to Roberto *et al.*'s finding that, in family triads where a member had prior *personal* experience of dementia acknowledgement of the PWMCI's problems was less likely than in triads where a member had previous *professional* experience of dementia (e.g. as a healthcare worker) (Roberto et al., 2011).

3.4.4 Attributions

Both PWMCI and advocates attributed the cognitive changes they noticed to a wide variety of causes. Subjects in both groups commonly reported that they felt the changes were no more than they would expect in their age group i.e. part of 'normal' ageing. Both the MCI and advocate groups frequently mentioned the PWMCI's physical health problems but often from different viewpoints: The MCI group tended to be more concerned about their physical than their mental health and tended to view them as separate entities whereas the advocates who talked of the linked PWMCI's physical health problems often did so in the context of attributing at least some of their cognitive symptoms to them. This is in keeping with the finding of previous studies, in which PWMCI most commonly attributed their cognitive changes to 'normal ageing' (McIlvane et al., 2008, Lingler et al., 2006, Beard and Neary, 2012, Roberts and Clare, 2012) whereas advocates expressed more uncertainty about their cause and often attributed them to physical health problems (Frank et al., 2006a, Blieszner et al., 2007)

Some PWMCI, however, did report uncertainty about the cause of their symptoms and very few were aware of the term 'mild cognitive impairment'. Uncertainty amongst PWMCI

regarding the cause of their symptoms has been identified in several other studies: Beard and Neary found that the participants in their qualitative study of experiences of MCI generally did not know how to describe MCI and were not sure that their doctor had ever defined it for them (Beard and Neary, 2012) and Frank *et al.* commented that most of the PWMCI they had interviewed '*were not given a specific name for their disorder*' (Frank *et al.*, 2006b). Similar to the subjects in this study, none of the 25 PWMCI interviewed in Roberts and Clare's study used the term MCI for their memory problems, despite having been given this diagnosis at their memory clinic appointment (Roberts and Clare, 2012).

In contrast to the MCI group, quite a few advocates were aware of the term MCI in relation to the PWMCI's cognitive problems. In Roberto *et al.*'s study of family triads about one third of the triads were categorized as displaying 'complete acknowledgement' which was described as '*all members indicating they fully acknowledged the diagnosis of MCI*' (Roberto *et al.*, 2011). However, even in this study it is not clear whether the care partners were aware of the specific term 'mild cognitive impairment' pertaining to the PWMCI's diagnosis. No studies have specifically focused on the awareness of MCI as a diagnostic term among caregivers of PWMCI; it is therefore unclear whether the knowledge of the term displayed by the advocates in this study was unusual, although the diagnostic uncertainty on the part of advocates described in many of the studies cited above suggests that it may be.

Attributions for cognitive symptoms are important as they can influence coping and important decisions (such as whether to seek medical assessment) in both PWMCI and advocates. Hurt *et al.*'s paper on help-seeking in adults with subjective memory complaint (SMC) provided some evidence for this (Hurt *et al.*, 2012). The authors also discussed the fact that attribution of cognitive changes to normal ageing or physical health problems appeared to be associated with a decreased likelihood of help-seeking whereas perceptions of serious consequences, a greater knowledge of AD and negative emotions were associated with a greater likelihood of help seeking.

3.4.5 Current Sources of Information and Support

The majority of PWMCI and advocates reported having received little or no information about MCI, although it is difficult to know how accurate these reports were as, at least in some cases, clinic letters were available for the PWMCI which specifically stated that such information *had* been provided. Regardless, even if verbal information had been provided it was clear that, in many cases, it had not been retained which suggests that provision of written information might have been more helpful. This apparent lack of provision of written information is in keeping with the findings of the survey of members of the American Academy of Neurology, only 27% of whom reported providing information in a written format

to people newly diagnosed with MCI (Roberts et al., 2010). Unfortunately no equivalent survey of practice in the UK has been carried out for comparison.

The sources of support described by both the MCI group and advocates were almost exclusively informal (i.e. family members and friends) – very few had received support from formal health or social care services. A lack of satisfactory provision of formal support for this group has been identified in other studies, for example a survey of memory clinic users in Holland which found that only 20% advocates were happy with the advice and support they received at the clinic (van Hout et al., 2001). Some caregivers in this study described feeling that they did not require any additional support at the current time (although they felt that they might do in the future) – a similar finding to Adams' study of caregivers of PWMCI (Adams, 2006).

Interestingly, although advocates were often angry or distressed by the perceived lack of information or support they had received, the PWMCI tended to be ambivalent about it. Previous studies have found that many carers of PWMCI do report increased support needs (Ryan et al., 2010, Blieszner and Roberto, 2010). No studies have specifically examined the PWMCI's perceptions of their support needs but in light of the decreased insight into their condition displayed by many it seems likely that this group may also underestimate their need for support. This may explain the discrepancy between PWMCI and advocate responses to the perceived lack of information and support described in this study.

3.4.6 Experiences of Health Services and Suggested Improvements

The MCI group tended to report that the experience of consulting the general practitioner (GP) about their cognitive problems was either positive or neutral, whereas advocates tended to have more negative impressions of the consultation – citing as issues of particular concern a dismissive attitude on the part of the GP or disappointment at not being able to discuss the PWMCI with the GP in confidence. In a meta-analysis of studies of GPs' ability to diagnose MCI only about 45% of cases were recognized (Mitchell et al., 2011) – this problem with recognition of MCI in primary care may explain the dismissive attitude encountered by some advocates. The discrepancy between PWMCI and advocate experiences within primary care has not been formally described in previous studies.

Reports from the PWMCI and their linked advocate of the mechanism by which the PWMCI presented to the GP were not always consistent – quite a number of the PWMCI reported that they consulted their GP about their memory spontaneously whereas most advocates reported that the consultation was either prompted by them (or another relative) or occurred when the PWMCI was consulting the GP about another health matter ('unintentional help-

seeking' a phenomenon noted in a previous study (Kuo and Shyu, 2010)). Again, this may reflect a lack of recall on the part of the PWMCI.

Both the PWMCI and advocates reported varying opinions of their experiences at memory clinic. Overall, more PWMCI than advocates reported positive experiences – often related to practical aspects of the memory clinic or to feeling relieved that they had not received a diagnosis of dementia. However, a significant proportion of both groups reported negative experiences, most commonly related to aspects of the assessment process or memory service or a perceived lack of information provision. These mixed reports are in keeping with the findings of the Dutch study of patients and carers attending memory clinics (van Hout et al., 2001) but no previous studies have specifically focused on the discrepancy between patient and caregiver experiences at memory clinics.

It may be that differing expectations on the part of patients and caregivers attending memory clinics go some way to explaining the discrepancies in the degree of satisfaction they describe. Indeed, a study of memory clinic users in Ireland found that, while patients described general expectations of being provided with 'help', carers had more specific expectations, such as identification of the cause of the patient's memory problems and provision of treatment (Cahill et al., 2008). In a similar vein, a German study of participation preferences of people with amnesic MCI found significant discrepancies between the degree of involvement in decision making that patients stated they would like compared to the degree of involvement that caregivers wanted them to have (Hamann et al., 2011). This finding may reflect different expectations on the part of patients and caregivers regarding the process of assessment at memory clinic.

The most common suggestion for improving services, from both the PWMCI and advocates, was the provision of more information. Both groups described a variety of similar topics on which they would like further information including coping strategies, treatment options, feedback of test results and what they could do to prevent further deterioration. Some advocates also mentioned that they would like information on sources of available support – a topic not brought up by the PWMCI. Information provision has been mentioned by several authors of observational studies in this area when making suggestions for improvements to services for PWMCI and their carers (Adams, 2006, Joosten-Weyn Banningh et al., 2008, Blieszner et al., 2007, Kuo and Shyu, 2010, Austrom and Lu, 2009, Lu and Haase, 2011). A number of advocates were interested in the possibility of psychological support, either for themselves and / or the PWMCI. Where advocates mentioned this topic it was either in the context of 'support groups' involving other PWMCI or advocates or individual sessions with a healthcare professional to discuss the difficulties they had encountered. Few of the other

suggestions made in the literature, such as cognitive rehabilitation and physical training, were spontaneously mentioned by the PWMCI or advocates in this study.

Many in the MCI group did not have any suggestions for improving services – often stating that they didn't feel improvements were required. Again, this attitude may be, at least in part, related to decreased insight in the PWMCI interviewed. In contrast, whereas some advocates did not feel that changes to services were needed (or, in some cases, possible), most did have suggestions for improvements: These generally related either to provision of information (as described above), changes in the assessment process or interaction with the memory services, for example improvements in communication.

3.5 Summary

The PWMCI and advocates in this study described noticing a range of cognitive changes and resulting functional limitations in keeping with the common symptoms of MCI. Many also described negative emotional consequences, although it was not uncommon for there to be a discrepancy between the PWMCI and the linked advocate in this area – with the advocate often describing a greater degree of distress than the PWMCI. Subjects who had had previous experience of dementia in a family member or close friend were particularly likely to express anxiety about the PWMCI's cognitive problems.

Attributions for symptoms varied in both the MCI and advocate group and differences between the two groups were also evident here: PWMCI most commonly ascribed their symptoms to 'normal ageing' whereas advocates were more uncertain as to the cause, often blaming physical health problems. Some advocates were aware of the term 'mild cognitive impairment' pertaining to the PWMCI's condition but few of the interviewees with MCI were.

Both groups described a perceived lack of provision of information and formal support by healthcare services, although advocates were much more likely to report that this had been a source of distress for them than PWMCI were. Overall, PWMCI were more likely to report neutral or positive experiences of health care services than advocates, whose reports were frequently negative. Most advocates had suggestions for improvements to services, whereas many of the PWMCI stated that they didn't think any improvements were necessary. The fact that PWMCI reported less dissatisfaction with their experiences of healthcare and less desire for changes to be made should be interpreted in light of the possible reduced recall and / or insight in this group. The commonest suggestion from both groups was that more information about topics related to MCI should be provided.

Overall, the results of the interviews suggest that the experiences of advocates differ markedly from the experiences of the PWMCI themselves in many areas. This should be taken into account designing assessment tools and support measures for these groups.

Chapter 4: Questionnaires

4.1 Introduction

The aims of this part of the study were twofold: Firstly, to produce draft versions of the outcome measures for people with mild cognitive impairment (PWMCI) and advocates, to refine the number of items in these measures thus producing the final versions of the outcome measures (the MCQ and MCQ-Carer) and to assess the domains being measured by the MCQ and MCQ-Carer items. The second aim was to establish which of the issues relating to healthcare identified by analysis of the interview data were deemed to be particularly important by a larger group of subjects. In order to achieve these aims, questionnaires incorporating the draft versions of the MCQ (or MCQ-Carer for advocates) and a survey about experiences of healthcare were administered to patients and advocates by post. In the first part of this chapter the methods by which the questionnaires were developed, administered and analysed are described. The advantages and limitations of the methods used are also discussed. In the second part of the chapter the results of factor analysis of the datasets obtained from administration of the draft versions of the outcome measures and the results of the descriptive analysis of the healthcare experiences survey data are given. In the final part of the chapter the final versions of the MCQ and MCQ-Carer are presented and the results of the descriptive analyses are discussed and summarised.

4.2 Questionnaire methodology

4.2.1 Initial Questionnaire Development

The analytical framework presented in Chapter 3 was used to guide analysis of the interview data (using NVivo software (version 9)) as described. NVivo is a qualitative data analysis software package which facilitates the organisation and structuring of text based data. The results of the coding process were used to identify the themes which recurred most frequently across the PWMCI and advocate interviews. Using these themes as a basis two questionnaires were developed – one for PWMCI and one for advocates. Themes were included in the draft versions of the questionnaires where they either recurred frequently or appeared particularly salient. Each questionnaire comprised two sections: The first section, which contained items relating to subject quality of life (QoL), was the draft version of the Mild Cognitive Impairment Questionnaire (MCQ) or, in the case of advocates, the Mild Cognitive Impairment Questionnaire for Carers (MCQ-Carer). The second section, the 'healthcare experiences survey', contained items relating to the subject's experience of healthcare services and opinions about how these might be improved. A section on 'subject background' was included to provide information on basic participant demographics and a

previously validated generic measure of health status (the Medical Outcomes Study short form health survey, 12 item version, version 2 (SF-12v2)) (Ware et al., 1996) was included at the end of the questionnaire.

The initial drafts of the questionnaires were reviewed by an expert panel consisting of: a Professor of Geriatric Medicine with a specialist interest in memory disorders, a consultant old age psychiatrist and a professor of Health Services Research with a specialist interest in the measurement of health related quality of life (HRQL) and the evaluation of patient experiences of medical care. As a result of this process the drafts were refined: items which were deemed to duplicate concepts were combined and those seeming to incorporate more than one concept were split. The QoL items included in the instrument were written, as far as possible, using language that reflected that used by the interview subjects.

A similar process was used to develop the 'healthcare experiences survey' part of the questionnaires. The initial drafts of the questionnaire were reviewed and refined by the group of individuals with a specialist interest in this field as described above. Some additional items, based on those used in the 15 item Picker Patient Experiences Questionnaire (PPE-15) (Jenkinson et al., 2002) were included on the basis of the professional judgement of the group. The PPE-15 is a validated, reliable measure of patient experience of healthcare which is used to measure the quality of care in several countries including the UK.

The QoL section was laid out as a set of 17 statements describing phenomena that the respondent might have experienced with a Likert type rating scale for the subject to complete (Likert, 1932). The response options given were: 'never / rarely / sometimes / often / always'.

The 'healthcare experiences survey' section was divided into sections entitled 'Your Experiences at the GP and Memory Clinic', 'Your Support and Sources of Information' and 'Improvements to Services and Information' each of which included several questions relating to these topics. The response options were a mixture of 'yes/no', Likert scales (with response options 'yes / to some extent / no') or 'tick all that apply'.

4.2.2 Focus Group Consultation

A draft of each of the questionnaires was produced as described above; these were shown to a focus group comprised of PWMCI and their advocates. The PWMCI were identified from a local research database; they were each sent an invitation to attend a two hour session, with a suitable advocate if possible, during which they would take part in an informal discussion about the questionnaire. Eleven PWMCI attended the focus group, each with an advocate. Focus group participant demographics are summarized in Table 1:

Group	Demographic	Value
PWMCI (N = 11)	Age (years) – range, mean	63-86, 75.9
	Gender (N male)	7
Advocates (N = 11)	Age (years) – range, mean	42-84, 71.0
	Gender (N male)	3
	Relationship to patient (%)	Spouse: 8
		Other relative 1
		Friend 2

Table 1. Questionnaire focus group participant demographics

At the beginning of the focus group session a brief introduction was given in which the nature of the study and the development of the questionnaires was outlined. It was emphasized that the main purpose of the session was for participants to comment on the contents, layout and ease of completion of the questionnaires and it was explained that it was not necessary to complete the questionnaires in their entirety (unless they wished to do so).

As mentioned above, participants were recruited from a local research database. Consequently many of the PWMCI had received their diagnosis during participation in research rather than via a clinical memory service. It was therefore mentioned during the introduction that those parts of the questionnaire relating to ‘experiences of memory services’ may not have been directly applicable to all members of the focus group. Those who had not had contact with memory services were asked to respond to the questions relating to that topic by simply commenting on their wording and layout rather than whether they seemed relevant to their experiences.

Participants were divided into a mild cognitive impairment (MCI) group and an advocate group and each participant was given the appropriate questionnaire and a sample version of the letter and information sheet which would accompany it when being used in the study. They were given approximately 30 minutes to read through the information and questionnaire and told that, at the end of that time, they would be asked for their feedback. They were given the option of either writing comments on the questionnaire or providing feedback verbally, whichever was their preference.

At the end of the 30 minute review period participants were asked individually for their feedback regarding questionnaire content, layout and ease of completion. Verbal responses

were audio-recorded and written responses collected. The responses were reviewed and summarized. Those points deemed to be particularly relevant and those raised by two or more participants, were taken into account in revising the draft questionnaires.

4.2.2.1 Focus Group Feedback Summary – Mild Cognitive Impairment Group

The PWMCI in the focus group gave feedback about most aspects of the questionnaires; this feedback is summarized below:

Overall, the feedback regarding the contents, layout and wording of the questionnaire was positive. Several minor formatting improvements were suggested. It was suggested that an option for 'not sure' or 'can't remember' be added for several questions where distant recall was required (specifically the timing of the last memory clinic appointment and questions pertaining to patient experiences during their appointments with the general practitioner (GP) and memory clinic). It was also suggested that not all PWMCI would necessarily have seen their GP about their memory prior to being referred to memory clinic and that there should be an option to state this in the relevant section.

Three questions appeared to require changes to their wording: The meaning of the question *'Would you have liked to have been assessed using tests that seemed more appropriate for mild memory problems?'* was queried by two subjects who asked for further clarification. Some subjects gave information in the 'other comments' section about the fact that, despite their best efforts and for various reasons, they did not feel it was possible for the health service to address all their needs. The question *'Do you feel that there's not much anyone can do for you at present?'* had been designed to describe this concept, but the fact that PWMCI included these comments elsewhere suggested that the wording of this question may not have adequately conveyed its meaning. The meaning of the QoL item *'Worry about feeling 'slowed down' in both mind and body'* was queried as appearing to refer to two separate concepts.

Few subjects suggested the inclusion of additional questions. However, several did mention in the 'other comments' section that a significant problem with their care had been a lack of coordination between services. This is something which reflected observations made by a number of the interviewees in the semi-structured interviews and which had not been included in the questionnaire at this point.

There were two areas where a clearer explanation about the rationale for collecting particular information appeared to be required: Several subjects queried the need to collect demographic information, particularly about ethnicity, and a number commented that the SF-12v2 questions appeared incongruous with the main part of the questionnaire to the extent that they were unsure about the need to complete them.

There were some minor difficulties in obtaining full feedback from all subjects attending the focus group: Despite the fact that the invitation to the feedback session was carefully worded to explain the nature of the questionnaire and the rationale for inviting each participant, two subjects felt that the questionnaire was not applicable to them as they did not agree that they had any memory problems. The fact that some of the subjects had not had any contact with memory clinics (having received their diagnosis via the local research group) also caused some difficulties: Despite the explanation at the beginning of the session that it was understood that not all subjects had been in contact with memory clinics and the directions simply to give general feedback about the sections pertaining to their experiences at clinic if this was the case, several subjects felt unable to comment on these sections at all if they had not attended a clinic.

4.2.2.2 Focus Group Feedback Summary - Advocates

Advocates in the focus group also provided feedback about most areas of the questionnaire designed for their use; this is summarized below:

Again, the overall feedback regarding the contents, layout and wording of the questionnaire was positive. Several advocates commented on how pleased they were to be asked about *their* experiences and health concerns as they felt that these issues had been neglected in their contact with healthcare services thus far.

It was pointed out by one participant that a more specific description of who the questionnaire was intended for would be helpful. Despite classifying herself as a '*relative who might have been affected by the PWMCI's memory problems*' (the definition of advocate given in the participant literature) she had contact with the PWMCI less than once a week on average and, consequently, felt she would be unable to answer many of the questions in the questionnaire.

Topics for some additional questions were suggested for inclusion and several of these reflected subjects which had been raised by advocates in the semi-structured interviews but not included in the questionnaire at this point: One participant suggested including an item about the 'loss of partnership' she had experienced, for example in social situations or for holidays. As in the MCI group, the lack of coordination of services was mentioned several

times and one participant commented that she was concerned about the practice of providing feedback about test results at a follow-up appointment and the delays involved in this.

Like the MCI group, some advocates queried the need to collect demographic information, particularly about ethnicity. Several also commented that the SF-12v2 questions not only appeared incongruous with the main part of the questionnaire but that, because the focus had shifted abruptly from the PWMCI to them, they were not clear who the SF-12v2 questions referred to.

As for the PWMCI who had not attended a memory clinic, several of their linked advocates also felt unable to comment on the sections of the questionnaire which asked about their experiences at clinic.

4.2.3 Final Revisions to Questionnaires

The feedback from the focus group described above was discussed by the expert panel involved in the initial questionnaire development. Following this process a number of changes were made to the draft questionnaires, the most important of which were as follows: In the PWMCI questionnaires a number of minor changes to the wording of questions were made to ensure clarity of meaning, the option to answer 'not sure' was added to several questions (particularly those where an element of recall was required), an item about 'coordination of healthcare services was added and a short explanatory paragraph was included before the SF-12v2 in order to emphasise and clarify the need for subjects to complete it. The same changes were made to the advocate questionnaires; in addition a guide as to who should complete the questionnaire was added (incorporating the suggestion that they should have contact with the PWMCI at least twice per week), as was a new item in the QoL section regarding 'loss' of the person with MCI and an emphasis on the fact that it was the advocate's views (rather than the PWMCI's) that were being sought. Full details of the changes made are given in Appendix 3. The final versions of the questionnaires are included in Appendix 4.

4.2.4 Questionnaire Administration

The questionnaires developed in the process described above were administered to a group of PWMCI and a group of advocates. Subjects with MCI included in this 'questionnaire stage' of the study were identified from memory clinics (and 'analogous services') and research databases. 'Analogous services' were defined as 'equivalent memory services being provided outside the 'traditional' setting of a hospital outpatient memory clinic', for example services provided in the patient's home by community mental health teams (CMHTs).

Inclusion criteria for PWMCI for this part of the study were: being 50 years of age or older, having had a diagnosis of MCI confirmed (using whichever criteria the diagnosing clinician applied) at a memory service within the past 12 months and being able to read and write in English.

'Recruitment packs' were given out at memory clinics (and 'analogous services') in Oxfordshire, Buckinghamshire, Northamptonshire, Leicestershire and North London to eligible patients who had been given brief verbal information about the study and had indicated that they were interested in taking part. The recruitment packs included a patient information sheet, the patient questionnaire, a pre-paid envelope in which to return the questionnaire and an advocate 'recruitment pack', in a separate, labeled envelope. The patient was asked to complete the questionnaire (either in clinic or at home) and to return it in the pre-paid envelope; they were also asked to pass the advocate 'recruitment pack' on to a suitable advocate if available.

'Recruitment packs' were also sent out to eligible subjects on the following research databases:

- Oxford Project to Investigate Memory and Aging (OPTIMA) research database
- Thames Valley Dementia and Neurological Diseases Research Network (DeNDRoN) Network research database
- Dementia Electronic Prescribing and Research Contact System' (DEEPARC) database (Oxfordshire and Buckinghamshire)
- Derwent Memory Clinic research database (Essex)
- Berkshire Healthcare NHS Foundation Trust Memory Clinic research database
- Northamptonshire Healthcare NHS Foundation Trust Memory Clinic research database
- Avon and Wiltshire Mental Health partnership NHS Foundation Trust Memory Clinic research database
- Imperial College Healthcare NHS Foundation Trust Memory Clinic research database
- The West London Dementia Registry (DemReg)
- The North Thames Dementia Registry (DemReg)

The recruitment packs included the same material as those used in clinic together with a covering letter explaining why the pack had been sent. Those subjects with MCI who had not replied within two weeks were sent a reminder letter about the study.

Advocates were recruited via PWMCI. Inclusion criteria for advocates were: being aged 18 or over, being a relative or friend of the PWMCI (and preferably in contact with them at least

twice per week) and being able to read and write English. As mentioned above, the patient 'recruitment pack' included a separate envelope containing the advocate 'recruitment pack'. The information given to the patient included a request for them to pass this pack on to '*a friend or relative who you feel may have been affected by your memory problems, and who you are in contact with at least twice a week*'. The advocate recruitment pack included a covering letter, an information sheet, the advocate questionnaire and a pre-paid envelope in which to return the questionnaire. The advocate was asked to complete the questionnaire and return it in the pre-paid envelope. The questionnaires for the PWMCI and the advocate supplied in each pack were given linked identifier codes, this was the only identifying information included on the returned questionnaires.

All subjects on the research databases used for recruitment had given prior consent to being contacted for the purposes of research. Consent to involvement in this study was implied by completion and return of the questionnaires (this was explained in the information supplied to subjects). Ethical approval for this part of study was obtained from the Southampton and South West Hampshire Research Ethics Committee (REC) (B) and the Research and Development (R&D) departments of each hospital trust involved.

The aim was to obtain at least 100 completed questionnaires from each group to ensure a sufficient sample size to allow evaluation of the psychometric properties of the outcome measures under development.

4.2.5 Analysis of Questionnaire Data

4.2.5.1 Data entry

The completed questionnaires returned by study subjects were collated and logged and the data was entered into an Excel (2010) spread sheet. Difficulties with data entry were addressed as follows: Where contradictory information was given (e.g. the age of an advocate and their specified relationship to the patient being incompatible) – the information was corrected if there was sufficient information in other sections of the questionnaire to do so, otherwise it was entered as it was given in the questionnaire. Those subjects stating that their last clinic appointment was more than 12 months ago were not excluded from data analysis. Where a 'multiple entry' was given (i.e. two or more boxes were ticked) for items where the instruction had specified 'tick one box only' the data was coded as missing. Where no box was ticked for items where the instruction had specified that an option be chosen (e.g. those with Likert scales or 'yes'/'no' options) the data was also coded as missing.

All data analysis was performed using the SPSS 18.0 computer programme. Analysis of the data from the demographic section, the healthcare experiences survey and the QoL questionnaire was carried out separately for the PWMCI group and the advocate group.

4.2.5.2 Statistical Analysis of Quality of Life Data

QoL items with high floor or ceiling effects were removed as were those with greater than 10% missing data. A figure of 40% or more of respondents answering 'never' or 'always' was used as a guide to identify items with high floor or ceiling effects respectively. Correlations were calculated between items to ensure none were very highly correlated (i.e. greater than 0.8) and therefore tapping the same issue. The data was then analysed using exploratory factor analysis in which items most strongly interrelated tend to gain high loadings on a single factor suggesting they are assessing the same underlying concepts. Varimax rotation was used to produce an orthogonal solution. Factors with an eigenvalue of greater than 1 were retained in the analysis. Where item loading was less than 0.4 on a factor the item was removed and where items loaded onto more than one factor they were included in the scale which seemed more theoretically meaningful.

Cronbach's alpha statistic (Cronbach, 1951) was used to assess the internal consistency of each domain identified by the factor analysis.

The total item scores for each domain identified by the factor analysis were transformed to create a scale score as follows: $\text{scale score} = ((\text{total of the raw scores of each item in the scale} - \text{the number of items in the scale}) / (\text{the maximum possible raw score of all the items in the scale} - \text{the number of items in the scale})) \times 100$. Scale scores ranged from 0 (best i.e. no problem at all) to 100 (worst i.e. maximum level of problem)

Construct validity was examined by correlation of the scale scores with scores from the SF-12v2 mental health component score (MCS). It was hypothesised that those scales relating to the emotional aspects of living with MCI would correlate most highly with the MCS i.e. the 'emotional effects' scale in the MCQ and the 'anxiety' and 'relationship effects' scales in the MCQ-Carer.

4.2.5.3 Statistical Analysis of the Healthcare Experiences Survey Data

Prior to analysing the 'healthcare experiences survey' data, responses for some questions were converted to problem scores: In several sections of the survey subjects were asked about aspects of the care they had received from healthcare services; the reply options

given for these questions were: 'yes', 'to some extent', 'no' or 'not sure'. For the purposes of analysis, the responses 'no' and 'not sure' were combined to give a 'problem score' and 'yes' was taken to indicate a 'no problem score'. In a small number of cases the item was coded in the opposite direction – in these cases the responses 'yes' and 'to some extent' were combined to give a 'problem score' and 'no' taken to indicate a 'no problem score'. In all cases a response of 'not sure' was coded as missing data.

The proportion of subjects falling into each response category for the healthcare experiences survey questions was calculated, using problem scores where these had been generated. For most questions the percentage of subjects falling into each response category was calculated as a proportion of the overall number of questionnaire respondents (i.e. including those who had not answered that particular question and were therefore counted as 'missing'). An exception to this was the question about whether the subject had been present when the linked PWMCI / advocate underwent their assessment at memory clinic – in this case the percentages were calculated as a proportion of those who had answered the question.

Multivariate regression analysis was used to explore the data from the PWMCI surveys further:

In order to establish whether PWMCI's opinions about improvements to various aspects of the memory clinic were related to their mental health (as measured by the SF-12v2 MCS) regression analysis was performed using subjects' problem scores for the 'possible improvements to memory clinic' items from the 'healthcare experiences survey' (together with age and sex) as independent variables and the SF-12v2 MCS as the dependent variable. To establish whether subjects' QoL, as measured by the MCQ, was related to their opinions about improvements to the memory clinic this regression analysis was repeated using the scale scores from the MCQ as the dependent variable.

Cronbach's alpha statistic (Cronbach, 1951) was calculated to establish whether the problem scores from the 'possible improvements to memory clinic' items could be summed to produce a valid summary score reflecting overall subject experience of healthcare services i.e. a 'healthcare experience summary score'.

In order to establish whether PWMCI's experiences of individual aspects of their care at memory clinic were related to the overall 'healthcare experience summary score' described above, regression analysis was performed using subjects' problem scores for 'going to the memory clinic' items (together with age and sex) as independent variables and their 'healthcare experience summary score' as the dependent variable.

4.2.6 Discussion of Methods Used

4.2.6.1 Questionnaire Development

The overall methods used to develop the questionnaire in this study were chosen as they have been shown to be effective in the development of similar questionnaires in the past and, in many areas, were compliant with the United States Food and Drug Agency's (FDA) guidance on the development of patient reported outcome measures (RPOMs) (US Department of Health and Human Services et al., 2009): For example, the FDA guidance suggests that, in the early phase of development, the domains intended be measured by the PROM should be guided by review of the relevant literature and expert opinion and that, in the subsequent phases of development, patient interviews, focus groups and qualitative cognitive interviewing should be used to refine these initial domains and generate the final items to be included in the instrument. Wackerbarth *et al.* used a similar method to that described here (semi-structured interviews followed by focus group discussion) to generate items for a survey of carers' reasons for seeking memory assessment for linked patients (Wackerbarth et al., 2002). They compared the items they generated by this method to two previous studies exploring the same topic which had used only literature reviews and focus groups to generate items. They found that their method generated 34 unique items not generated by the two previous studies and missed only 6 identified by those studies. They concluded that researchers should consider generating survey items for undocumented phenomena using *'informant interviews followed by focus groups to confirm themes because of the comprehensiveness of items generated'*.

To ensure content validity, the content and wording of the items in the questionnaire were based on the concepts raised, and language used, by the interview subjects in the first stage of the study. This is in accordance with the FDA guidance, which states: *'The exact words used to represent the concepts measured by domain or total scores should be derived using patient input to ensure the conclusions drawn using instrument scores are valid'*. Revision of the draft questionnaires with input from the focus group is also in line with the guidance, which states that the target population *'should be involved in evaluating the completeness of item coverage and performing initial an assessment of.. clarity and readability'*.

Where interview subjects had displayed poor recall about a particular topic area, for example PWMCI's' experiences of consultation with their GP, the number of frequently recurring items relating to that topic tended to be low. Therefore, for these topics, professional judgement was used to include additional items in the questionnaires which seemed likely to be relevant to the target study population. These items were selected from those included in

the short form version of the PPE-15 questionnaire, as described above (Jenkinson et al., 2002).

It was decided that questions about potential improvements to services should relate to memory services only as it was intended that these should be the main focus of any draft guidance produced as a result of the study. It was not intended that guidance for GPs was should be produced for two reasons: firstly, the topic of patient satisfaction with GP consultations is a large one and outside the scope of this research project. Secondly, as the subjects interviewed in the first part of this study were recruited following memory service consultations (rather than following consultations with GPs specifically about memory) it was difficult to be certain what the agenda of initial consultation with the GP actually was. Therefore subjects' comments about their GP's management of their memory problems may not have reflected the GP's usual practice in a consultation about memory.

Careful consideration was given to the response options provided in the questionnaire. A Likert scale was chosen for the MCQ and MCQ-Carer because it has been successfully used in other well validated, widely used questionnaires e.g. The 40 item ALS assessment questionnaire (ALSAQ-40) (Jenkinson et al., 1999), the Endometriosis Health Profile-30 (EHP-30) (Jones et al., 2001) and the Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) (Ware and Sherbourne, 1992). For the 'healthcare experiences survey' section, an option to answer 'not sure' was included for questions which required the respondent to remember specific details (e.g. those relating to experiences at the GP appointment). This was done to give respondents who were unable to recall their experiences the option of not answering the question (as suggested by the focus group). This had two advantages: it reduced the likelihood that respondents might attempt to guess at answers if they had poor recall and avoided any distress which might be caused by the subject having to state '*I can't remember*'.

Construct validity of the MCQ and MCQ-Carer was assessed by comparing results from these measures with similar dimensions of the SF-12v2. The SF-12v2 is a generic, multi-purpose health survey which provides measures of functional health and well-being as well as psychometrically based summary measures of physical and mental health. It was included in the survey pack so that the results from the QoL section could be compared with the SF-12v2 mental health summary measure to allow an estimation of construct validity. This instrument was chosen because it has been well validated, including for postal use (Lee et al., 2008a, Chen et al., 2009, Martinez et al., 2008) and extensively used. Although there are no published studies in which it has been validated for use specifically in people with cognitive impairment the SF-12v2 has been shown to be psychometrically sound for

assessing QoL in people with severe mental illness such as psychosis and major mood disorders (Salyers et al., 2000). In addition, it has been shown that there is a high degree of correspondence between summary physical and mental health measures estimated using the SF-12v2 and SF-36 (Gandek et al., 1998) and that the SF-36 has reasonable psychometric properties for assessing QoL in people with mild to moderate dementia (specifically those with a Mini-Mental State Examination score of 15 or greater) (Novella et al., 2001).

4.2.6.2 Questionnaire Administration

The methods by which the questionnaires were administered were chosen to allow the largest sample to be obtained whilst maximizing the likelihood that the study sample remained representative of the target population and that ethical research principles were adhered to.

The inclusion criteria for PWMCI for this stage of the study were similar to the first (interview) stage and chosen for similar reasons i.e. to maximize the likelihood that subjects' diagnoses were both accurate and reflected those made in clinical practice. The main difference was that the inclusion criteria for the questionnaire stage allowed recruitment of people who had had their diagnosis of MCI confirmed (i.e. not necessarily newly made) within the preceding 12 months (rather than 6 months). These criteria were chosen so that the study sample would include people who had been living with MCI for some time as it is likely that people with a relatively long history of MCI will form part of the clinical population to whom the results of the study are intended to apply. The inclusion criteria for advocates for this stage of the study included the stipulation that the advocate should be someone with whom the PWMCI had contact 'at least twice per week'. This suggestion was included (following feedback from the focus group) to ensure that advocates being given questionnaires had had sufficiently frequent contact with the PWMCI to complete the questionnaire in an accurate and meaningful way.

PWMCI were recruited from memory clinics (and analogous services) and research databases in various regions. Whilst this increased the burden of administrative work (e.g. obtaining REC and R&D approval for multiple sites) it had the advantage of providing a geographically diverse study population who had had contact with a range of different healthcare services. The inclusion of subjects listed on research databases allowed recruitment of a sufficiently large sample for the purposes of the study which would otherwise not have been possible in the time available. It may, however, have introduced a degree of selection bias, as some of these subjects had taken part in other research projects (e.g. the Oxford Project to Investigate Memory and Aging and the 'Thinking Fit' project in

Essex) which, whilst not part of their standard clinical care, may have influenced their experiences of living with MCI and hence their questionnaire answers. All advocates were recruited via PWMCI to ensure that the linked PWMCI was aware of, and in agreement with, the advocate's involvement in the study.

Consent for involvement in this part of the study was implied by completion and return of the questionnaire in order to reduce the administrative burden for the study subjects. The implied consent process was clearly explained in the information supplied with the questionnaires. Questionnaires were marked with an identifying code, the subject details for PWMCI corresponding to each code were known only to the author. This allowed a record to be kept of the return rate from the various recruitment sources and meant that reminder letters, where necessary, could be sent out at the appropriate time to PWMCI recruited from research databases. It also provided reassurance for participants that their answers would be confidential between them and the researcher - something which is particularly important for those commenting on clinical services who might otherwise feel unable to be honest about their experiences.

The estimated number of completed questionnaires required was calculated based on the number of items in the QoL section. It is known that, in order to produce reliable results, such questionnaires should be administered to approximately 3 subjects per item with a minimum sample size of 100, preferably 120 for a conservative (i.e. large) sample size (Barrett and Kline, 1981, Costello and Osborne, 2005) . As there were 17 and 18 items in the QoL sections of the PWMCI and advocate questionnaires respectively a minimum sample size of 100 was set.

4.2.6.3 Questionnaire Analysis

The conventions used for data entry described in Section 4.2.5.1 were set for the following reasons: Despite the inclusion criteria stipulating that PWMCI should have been seen in a memory clinic (or analogous service) within the preceding 12 months, respondents who stated that their most recent clinic appointment was more than 12 months ago were not excluded from the analysis. This group was included because the recruitment mechanisms used strongly suggest that patients recruited for the study *were* seen within 12 months – therefore it is likely that those stating that their appointment was greater than 12 months previously did so due to poor recall rather than the appointment genuinely being outside that timeframe. As this group may represent a cohort with particularly pronounced memory impairment, and therefore possibly a particular set of support needs, it was decided that they should not be excluded from the analysis. Furthermore this group was small in number, including only 6 subjects

There are various options for dealing with 'multiple entry' data; the option to code it as 'missing' was chosen as this allows easy identification, via the high proportion of missing data, of items which are ambiguous and therefore result in a high rate of 'multiple entry' data and which should therefore be considered for removal from the final version of the measure. This approach to dealing with 'multiple entry' data is in line with that suggested in the SF-12 User's Manual (Ware et al., 2010)

QUALITY OF LIFE DATA

The QoL data from the questionnaires was analysed to produce the final versions of the MCQ and MCQ-Carer. Data analysis was conducted using SPSS version 18.0, in accordance with accepted methods for this type of data analysis (Streiner and Norman, 2003, Kline, 1999) including the FDA guidance on the development of PROMs (US Department of Health and Human Services et al., 2009) e.g. removal of items with a high proportion of missing data, those which had high floor or ceiling effects (with 40% subjects giving a 'never' or 'always' response used as a guide for the latter) and those which were redundant. As there was no pre-existing hypothesis about the structure of the underlying variables, principle components analysis was used to explore the dimensions underlying the questionnaire. As per convention, factors with eigenvalues greater than 1 were retained (Fayers and Machin, 2000). Orthogonal varimax rotation was used to provide a simple structure where each factor included the smallest number of items. As per generally accepted criteria, items were included in a factor where they had loadings of 0.4 or greater and if items loaded on more than one factor they were included in the scale which seemed more theoretically meaningful (Fayers and Machin, 2000). The Cronbach's alpha coefficients were high for all dimensions the MCQ and MCQ-Carer (Sections 4.3.1.1 and 4.3.1.2 for details) which suggests that the measures are reliable.

Scores for each domain were transformed into scale scores with a minimum possible score of 0 and maximum possible of 100 to facilitate interpretation of scores and comparison between scales and groups.

The construct validity of the MCQ and MCQ-Carer was examined by correlation of their scale scores with the SF-12v2 MCS – again in keeping with accepted practice (Streiner and Norman, 2003) and FDA guidance (US Department of Health and Human Services et al., 2009). It was hypothesised that the scores for the MCQ and MCQ-Carer scales relating to underlying 'emotional' constructs would be most highly correlated to the SF-12v2 MCS score i.e. both scale scores for the MCQ and the 'anxiety' and 'relationship effects' scores for the MCQ-Carer.

HEALTHCARE EXPERIENCES SURVEY DATA

For questions regarding respondents' experiences of healthcare and desired improvements to services the data was converted to dichotomous 'problem scores' to facilitate statistical analysis. This approach also has the advantage of ensuring that sample sizes in the 'problem' and 'no problem' groups do not become too small – a risk when the population is divided between the original 4 response categories of 'yes', 'to some extent', 'no' and 'not sure'. This method has been used successfully in other patient experience questionnaires such as the PPE-15 (Jenkinson et al., 2002). It is particularly useful in this context as the combination of two response categories (i.e. that indicating the problem is present and that indicating it is present 'to some extent') to form a 'problem' score (as opposed to the single response, indicating that the problem is not present which generates a 'no problem' score) 'weights' the questionnaire towards detecting problems.

The questionnaire items relating to 'possible improvements to memory clinic services' were chosen as a potential marker of subjects' overall experiences of healthcare because many of these items reflect respondents' general opinions about their experiences rather than relating to one specific time point or detail of their contact with healthcare services (cf. the items about subjects' experiences at the GP and memory clinic). Multiple regression analyses were performed to establish whether these items were related to respondents' mental health (as measured using the SF-12v2 MCS) with the intention that, if the analysis did show a significant relationship, the scores for the 'desired improvements to memory clinic services' could be used as a measure of overall subject experience of healthcare.

Regression analyses were also performed to establish whether the items relating to 'possible improvements to memory services' were related to QoL as measured by the scale scores from the MCQ so that comment could be made about the effect of subjects' experiences of healthcare on the various aspects of QoL measured by these scales and not just mental health (as measured by the SF-12v2 MCS).

The validity of summing the individual items relating to 'desired improvements to memory clinic services' to produce a summary score was also tested (by calculating the Cronbach's alpha) to establish whether this could be used as a potential single 'summary' score of subjects' experiences. Correlations between this summary score and individual aspects of respondents' experiences at the memory clinic were then sought to establish whether experience in any of the individual elements could 'predict' overall experience.

4.3 Questionnaire Results

4.3.1 Outcome Measure Results

4.3.1.1 People With Mild Cognitive Impairment: The Mild Cognitive Impairment Questionnaire (MCQ)

The final versions of the draft questionnaires, developed as described in the first part of this chapter, were administered to people with mild cognitive impairment (PWMCI).

Approximately 280 questionnaires were distributed to patients in clinics (and at analogous services) and posted to PWMCI listed on research databases. Two hundred and twenty five questionnaires were sent to subjects on research databases, 132 (59%) of which were returned. One hundred and seventy recruitment packs were distributed to memory services 55 of which were given to patients, 18 of these (33%) were returned. Therefore in total 150 completed questionnaires (54%) were returned, 88% of them by subjects recruited from research databases. 4 subjects were excluded as their age was below the minimum age cut-off and therefore 146 eligible subjects were included in the analysis. The subjects ranged in age from 52 to 91 years with a mean of 75.4 and a standard deviation (SD) of 7.6. The remainder of the demographic details of the subjects are given in Table 2

Characteristic		Number	%
Gender	Male	82	56.2
	Female	61	41.8
Ethnicity	White	135	92.5
	Asian	7	4.8
	Mixed	1	0.7

Table 2. Demographic details of questionnaire subjects with mild cognitive impairment

The Medical Outcomes Study short form health survey, version 2 (SF-12v2) Physical Health Component Scores (PCS) for PWMCI ranged between 18.5 and 66.4 with a mean of 46.1 and a standard deviation (SD) of 11.5. Comparing these results to published population norms (which are given in Appendix 5) revealed that 66.1% of subjects had PCS at or below the 50th centile for the general population. However, when compared to norms for an age group more representative of the PWMCI in the study (who had a median age of 76.5, therefore a comparison to over 75 year olds in the general population was made) (Ware et al., 2007) only 27.4% had a PCS at or below the 50th centile for this age group. SF-12v2

Mental Health Component Scores (MCS) ranged between 22.0 and 63.4 with a mean of 46.8 and a standard deviation (SD) of 9.0; 70.4% of subjects had MCS at or below the 50th centile for the general population and 64.5% were below the 50th centile when compared with norms for the over 75 age group.

ITEM REDUCTION AND SCALE GENERATION

The 17 item QoL questionnaire, developed as described in the first part of this chapter, was completed by 146 eligible subjects.

No items had >10% missing data and none were very highly correlated with other items.

Four items were removed because of floor effects, these were (% respondents selecting 'never' given in brackets): not being able to take part in hobbies or social events' (42.8%), 'feeling that you have had to cover your memory problems up to avoid upsetting someone (51.1%), 'worry about a change in your personality' (39.3%), 'feeling unable to talk to friends or relatives about your memory problems because it is upsetting or embarrassing' (38.6%).

A factor analysis was performed on the remaining 13 items; two domains were identified accounting for 61.8% of the total variance:

Emotional effects (6 items): This domain addresses the emotional effects of living with MCI including irritation/frustration, anxiety, low mood, concern about the future, worry about the reactions of others and worry that their memory problems are more severe than those of their peers. The Cronbach's alpha for this domain is of 0.91 which indicates high internal consistency reliability by the accepted standard (Streiner and Norman, 2003, Cronbach, 1951, Nunnally and Bernstein, 1994).

Practical concerns (7 items): This domain covers the practical effects of living with MCI including worry about: having forgotten things (e.g. names), plans or appointments, problems with conversation due to memory difficulties, feeling generally 'slowed down' or less independent and concern about upsetting others. The Cronbach's alpha for this domain is 0.85 which indicates good internal consistency reliability.

The rotated component matrix resulting from the factor analysis is given in Table 3.

	Component	
	1	2
Worry that you have forgotten things such as recent conversations or the names of things or people	.382	.661
Worry that you have had problems constructing a sentence when talking	.261	.577
Worry that you have forgotten what you had planned to do	.335	.714
Worry that you have had problems remembering appointments or important dates, such as birthdays	.174	.794
Worry about feeling generally 'slowed down'	.308	.632
Worry that you have upset other people because of your memory problems	.362	.623
Feeling that you have become less independent because you have had to rely on your partner or other people to help you remember things	.407	.650
Irritation or frustration about your memory problems	.723	.356
Feeling worried about your memory problems	.823	.351
Feeling downhearted or depressed about your memory problems	.826	.336
Worry about other people's reactions to your memory problems	.606	.403
Worry that your memory problems are more severe than those of other people of your age	.716	.367
Worry about your memory problems getting worse in the future	.825	.250

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization. Rotation converged in 3 iterations.

Table 3. Rotated component matrix resulting from factor analysis of questionnaire quality of life data for subjects with mild cognitive impairment

The correlations of items to their domain totals and the internal consistency reliability of the domains are shown in Table 4.

Domain	Items	Corrected item to total correlation	Cronbach's alpha
Emotional effects	Irritation or frustration about memory	0.71	0.91
	Worry about memory	0.82	
	Feeling downhearted about memory	0.82	
	Worry about others' reactions to memory problems	0.64	
	Worry that memory is worse than peers'	0.73	
	Worry about memory worsening in the future	0.77	
Practical concerns	Worry about forgetting things e.g. names	0.64	0.85
	Worry about sentence construction	0.51	
	Worry about forgetting plans	0.67	
	Worry about forgetting appointments	0.65	
	Worry about feeling slowed down	0.59	
	Worry about upsetting others because of memory problems	0.61	
	Feeling less independent	0.66	

Table 4. Correlation of MCQ items to total correlations and internal reliability of domains

EVALUATING CONSTRUCT VALIDITY

The 'emotional effects' scale was adequately correlated with the SF-12v2 MCS ($\rho = -.43$, $p < 0.001$, $N = 111$) as was the 'practical concerns' scale ($\rho = -.56$, $p < 0.001$, $N = 113$). The negative correlations reflect the fact that the MCS and the MCQ scale scores operate in different directions: a higher MCS indicates 'better' mental health whereas higher MCQ scale scores indicate 'worse' outcomes.

FINAL OUTCOME MEASURE

The final version of the MCQ, developed as described above, is shown in Appendix 6.

RESULTS OF QUALITY OF LIFE DATA FOR PEOPLE WITH MILD COGNITIVE IMPAIRMENT

The scale scores for PWMCI in the study are shown in Table 5.

Scale	Mean (SD)	N	Range of Scores	N (%) minimum score	N (%) maximum score
Emotional effects	46.60 (24.19)	137	0 - 100	2 (1.5)	1 (0.7)
Practical concerns	45.43 (19.90)	139	0 - 96	1 (0.7)	0 (0.0)

Table 5. Descriptive statistics for the dimensions of the MCQ from results of the survey.

SD = standard deviation, N = number

4.3.1.2 Advocates: The Mild Cognitive Impairment Questionnaire for Carers (MCQ-Carer)

Of the approximately 280 questionnaires given out via patients in clinics (and analogous services) and posted to PWMCI listed on research databases 101 completed questionnaires (36%) were returned by advocates. 3 subjects were excluded as the linked PWMCI was ineligible for the study therefore 98 advocates were included in the analysis. Respondents were aged between 21 and 84 years with a mean age of 66.3 and a SD of 12.8. The remaining demographic details of the advocates are summarised in Table 6.

Characteristic		Number	%
Gender	Male	26	26.5
	Female	72	73.5
Ethnicity	White	91	92.9
	Asian	3	3.1
	Black	3	3.1
Relationship to PWMCI	Spouse	67	68.4
	Offspring	17	17.3
	Other relative	5	5.1
	Friend	6	6.1
	Other	3	3.1

Table 6. Demographic details of the advocate questionnaire subjects

SF-12v2 PCS for advocates ranged between 19.1 and 65.5 with a mean of 49.6 and a standard deviation (SD) of 10.8. Comparing these results to published population norms revealed that 54.6% of subjects had PCS at or below the 50th centile for the general population. However, when compared to norms for an age group more representative of the advocates in the study (who had a median age of 69.5 years, therefore a comparison to 65 – 74 year olds in the general population was made) only 26.5% subjects had a PCS at or below the 50th centile for this age group (Ware et al., 2007). Population norms for the SF-12v2 are given in Appendix 5. SF-12v2 MCS ranged between 20.7 and 68.7 with a mean of 48.8 and a standard deviation (SD) of 10.0; 51.6 % of subjects had MCS at or below the 50th centile for the general population and 57.0% below the 50th centile for the 65-74 age group.

ITEM REDUCTION AND SCALE GENERATION

The 18 item QoL questionnaire, whose development was described in the first part of this chapter, was completed by 98 eligible subjects.

No items had >10% missing data and none were very highly correlated with other items.

Three items were removed because of floor effects, these were (% respondents selecting 'never' given in brackets): feeling worried about leaving the PWMCI by themselves' (42.9%), 'feeling unable to talk to the PWMCI about their memory problems (42.9%), 'feeling unable

to talk to others about the PWMCI's memory problems' (38.5%). A further item 'feeling less worried about the PWMCI's memory problems than they seem to be' was removed as it appeared to duplicate the concept captured by the item 'feeling more worried about the PWMCI's problems than they seem to be'. To ensure that the removal of this item did not compromise the internal consistency reliability of the domain in which it had been included (the 'anxiety' domain described below) Cronbach's alpha was calculated for the domain with the item included and with it removed. The alpha value when the item was removed (0.86) was greater than when it was included (0.76) suggesting that internal consistency reliability was not reduced by the removal of the item 'feeling less worried about the PWMCI's memory problems than they seem to be'.

A factor analysis was performed on the remaining 14 items; three domains were identified accounting for 65.7% of the total variance. The rotated component matrix resulting from the factor analysis is shown in Table 7.

Anxiety (6 items): This domain addresses the emotional effects of being an advocate of a PWMCI, most of which incorporate an element of anxiety: feeling worried or depressed about the memory problems, feeling more worried about the memory problems than the PWMCI, feeling uncertain about whether 'prompt' the PWMCI and feeling worried or uncertain about the future. The Cronbach's alpha for this domain is 0.87 which indicates good internal consistency reliability by the accepted standard.

Burden (5 items): This domain covers the practical effects of being an advocate of someone with MCI including worry about: the PWMCI having forgotten things such as appointments, that they are having more difficulty with finances and paperwork, that their personality has changed and that they are less independent and feeling increasingly burdened by having to help out with financial and administrative matters. The Cronbach's alpha for this domain is 0.85 which indicates good internal consistency reliability by the accepted standard.

Relationship (3 items): This domain covers the effects that MCI had had on the relationship between the advocate and the PWMCI including: frustration, relationship difficulties and a feeling of 'losing the person they used to know'. The Cronbach's alpha for this domain is 0.67 which indicates acceptable internal consistency reliability by the accepted standard.

	Component		
	1	2	3
Worry that they have forgotten things such as appointments, names or recent events	.445	.631	-.077
Worry that they have had problems dealing with bills, finances or paperwork	.041	.900	.072
Worry about a change in their personality e.g. they seem more anxious or irritable	.357	.589	.312
Feeling that you are increasingly burdened by having to help out with dealing with bills, finances or paperwork	.369	.632	.388
Feeling that they are less independent	.442	.585	.273
Feeling unsure about whether to try strategies to 'prompt' your relative / friend's memory such as trying to let them remember something by themselves	.534	.339	.167
Feeling downhearted or depressed about their memory problems	.583	.284	.500
Feeling frustrated or angry about their memory problems	.005	.089	.849
Feeling worried, anxious or stressed about their memory problems	.680	.216	.433
Feeling more worried about their memory problems than they seem to be	.673	.130	.346
Worry about memory problems getting worse in the future	.846	.244	-.041
Uncertainty about the future	.849	.240	-.045
Difficulties in your relationship e.g. increased arguments	.292	.487	.455
Feeling you are losing the person you used to know	.645	.373	.391

Extraction Method: Principal Component Analysis. Rotation Method: Varimax with Kaiser Normalization.
Rotation converged in 5 iterations.

Table 7. Rotated component matrix resulting from factor analysis of questionnaire quality of life data for advocates

The correlations of items to their domain totals and the internal consistency reliability of the domains are shown in Table 8.

Domain	Items	Corrected item to total correlation	Cronbach's alpha
Anxiety	Feeling unsure whether to try strategies to prompt the PWMCI's memory	0.51	0.87
	Feeling downhearted about the memory problems	0.68	
	Feeling worried about the memory problems	0.73	
	Feeling more worried about the memory problems than the PWMCI	0.64	
	Worry about the memory problems getting worse in the future	0.74	
	Uncertainty about the future	0.71	
Burden	Worry that the PWMCI has forgotten things e.g. appointments	0.59	0.85
	Worry that the PWMCI has problems dealing with bills or paperwork	0.67	
	Worry about a change in the PWMCI's personality	0.62	
	Feeling increasingly burdened by having to help out with bills etc.	0.74	
	Feeling that the PWMCI is less independent	0.69	
Relationship	Feeling frustrated or angry about the memory problems	0.36	0.67
Relationship	Difficulties in the relationship	0.53	

Domain	Items	Corrected item to total correlation	Cronbach's alpha
(continued)			
	Feeling of losing the person they used to know	0.58	

Table 8. Correlation of MCQ-Carer items to total correlations and internal reliability of domains

EVALUATING CONSTRUCT VALIDITY

The 'anxiety scale was correlated with the SF-12v2 MCS ($\rho = -.60$, $p < 0.001$, $N = 80$) as were the 'burden' scale ($\rho = -.40$, $p < 0.001$, $N = 81$) and the 'relationship' scale ($\rho = -.47$, $p < 0.001$, $N = 83$). Again, the negative correlations reflect the fact that the MCS and the MCQ-Carer scale scores operate in different directions: a higher MCS indicates 'better' mental health whereas higher MCQ-Carer scale scores indicate 'worse' outcomes.

FINAL OUTCOME MEASURE

The final version of the MCQ-Carer, developed as described above, is shown in Appendix 7.

RESULTS OF ADVOCATE QUALITY OF LIFE DATA

The scale scores for advocates in the study are given in Table 9.

Scale	Mean (SD)	N	Range of Scores	N(%) minimum score	N(%) maximum score
Anxiety	52.06 (20.86)	95	0 - 100	1 (1.1)	1 (1.1)
Burden	48.26 (24.05)	95	0 - 100	2 (2.1)	1 (1.1)
Relationship	38.18 (24.26)	98	0 - 100	10 (10.2)	1 (1.0)

Table 9. Descriptive statistics for the dimensions of the MCQ-Carer.
SD = standard deviation, N = number

4.3.2 Experiences of Healthcare Survey Results

The draft QoL measure and the 'healthcare experience survey were distributed together in the form of one single questionnaire, therefore the number of surveys distributed and

returned, and the demographic details of the respondents are identical for the QoL measure and the healthcare experiences survey

4.3.2.1 Patient Survey

EXPERIENCES OF CARE AT THE GENERAL PRACTITIONER

Most (87.0%) of the respondents had consulted a GP about their memory problems with the majority of those who had (61.4%) stating that '*they had decided to talk to their GP about their memory because they were worried*'.

As described in the 'Methods' section of this chapter, the responses to the questions about PWMCI's experiences when they consulted the GP about their memory problem were converted to a 'problem score' for each item. The percentages of PWMCI reporting a problem with the various aspects of GP care are given in Table 10. PWMCI most commonly reported problems with aspects of their involvement in the care given by the GP: either wanting to be more involved in their care (40.4%), not being given enough information about what was happening (39.1%) or not having all their questions answered (23.2%).

Aspect of Care	% Indicating a Problem
GP acted quickly to get things done	19.2
Confident in the GP's ability	15.2
GP took problems seriously	17.9
Given enough information about what was happening	39.1
Given right amount of time with the GP	17.9
GP answered all questions	23.2
GP talked as if patient wasn't there	6.0
Given enough privacy	1.3
Would like to have been more involved in decisions	40.4

Table 10. Percentage of people with mild cognitive impairment reporting a problem with aspects of general practitioner care in the 'healthcare experiences survey'

19 subjects, who indicated that they had not consulted a GP about their memory problems, were excluded from this part of the data analysis.

EXPERIENCES OF MEMORY CLINICS

All respondents had attended a memory clinic; of those who specified when they had attended the clinic the majority (76.9%) had done so within the preceding 6 months and almost all (95.5%) within the preceding 12 months.

Subjects were asked about their experiences at memory clinic; problem scores for the responses are summarised in Table 11. The most commonly reported problem was concern, prior to the clinic appointment, that their memory problems might have been due to a more serious diagnosis than MCI (64.2%). Other commonly reported problems related to the PWMCI's involvement in their care: not being given all the information that they wanted (31.1%), the results of tests not being explained in a way that the PWMCI could understand (29.1%) and not feeling sufficiently involved with decisions about their care (21.9%). Finding the tests performed in the memory clinic stressful or upsetting was also a commonly reported problem (26.5%).

Aspect of Care	% Indicating a
----------------	----------------

	Problem
Found tests stressful / upsetting	26.5
Wait for first appointment too long	23.2
Gap between appointments too long	19.9
Given all the information wanted	31.1
Treated with dignity and respect	5.3
Prior to appointment, worried that problem was serious	64.2
Clinic well organised	8.6
Felt sufficiently involved with decisions	21.2
Results of tests explained in a comprehensible way	29.1

Table 11. Percentage of people with mild cognitive impairment reporting a problem with aspects of memory clinic care in the healthcare experiences survey

72.2% of respondents indicated that they had had their assessments at memory clinic in the presence of a friend or relative and the majority of these patients (97.8%) were satisfied with this arrangement. 23.0% patients indicated that they had been assessed without their relative or friend present, 89.7% were satisfied with this arrangement. 20 subjects answered this question in a 'contradictory' fashion, indicating that an advocate both had and had not been present during their assessment, and were therefore excluded from this part of the data analysis.

CURRENT SOURCES OF INFORMATION AND SUPPORT

The most common sources of practical and / or emotional support reported by PWMCI were spouses (62.5%) and other family members (43.8%); notably only 6.3% reported receiving 'formal' support from health or social care services. Some respondents (9.4%) reported that they had not received any help or support at all and a sizeable minority (23.4%) reported that they didn't feel they needed any support at the current time. Of the 12 PWMCI reporting that they did not receive any help or support, just over half (N = 7) also indicated that they did not feel that they needed any help or support at the current time.

18 respondents reported that they did not receive any support but simultaneously indicated sources from which they had received it – these subjects have been excluded from this part of the data analysis (the data was treated as missing).

By far the most commonly reported source of information about memory problems was the 'memory specialist seen by the patient' with 72.7% patients indicating that they had found them a helpful source of information. Interestingly 'friends and family' were the second most commonly reported source of information (35.2%) – outranking 'written material such as leaflets' (28.9 %) and 'other healthcare professionals' (28.9%). Only 7.8% had obtained information from the internet.

18 respondents reported that had not received any information but simultaneously indicated sources from which they had received it – these subjects have been excluded from this part of the data analysis (the data was treated as missing).

POTENTIAL IMPROVEMENTS TO SERVICES

The proportions of PWMCI endorsing each of the suggested improvements to services are summarised in Table 12. The most popular suggestions were: the provision of more information at the clinic appointment (39.7%), assessment with tests that seem 'more appropriate' for the nature of their problem (39.0%) and being given more warning of what was going to happen at the assessment (32.2%). The concept of 'being assessed using tests that seemed more appropriate for the problem' was one which was frequently raised by interview subjects in the first stage of the study – many of whom felt that the tests they had undergone seemed more appropriate for people with more severe memory problems such as dementia and that, consequently, they may not have detected the less pronounced deficits caused by their mild cognitive problems.

Only 21.2% respondents felt that they needed any extra support from the clinic at the current time and only 24.7% felt that it was possible for the clinic to provide such support.

Suggested improvement to service	% Endorsing
Provision of more information at the appointment	39.7
More time at the assessment	18.5
More warning of what was going to happen at assessment	32.2
Shorter assessment	10.3
More appropriate tests	39.0
More reassurance from staff	18.5
Better coordination of healthcare	18.5
Feels needs extra help / support from memory clinic	21.2
Feels possible for memory clinic to provide extra help / support	24.7

Table 12. Percentage of people with mild cognitive impairment endorsing suggested improvements to services in the healthcare experiences survey

Aside from the question about potential improvements to services, subjects were also asked which topics they would like further information about and what format they would like to receive such information in. In response to the question regarding 'topics on which they would like further information' a majority of respondents indicated that they would like more information in all of the suggested topic areas with the most commonly requested being: what the PWMCI can do to prevent their memory getting any worse (93.8%), tips on how to get round memory problems (86.5%) and prognosis (82.9%). The least popular answer to this question was 'provision of test results' – only 58.2% of respondents indicated that they would like further information on this topic. In response to the question about how subjects would like information to be provided the most popular choices were: 'provision of information in a 'face-to-face' setting by a healthcare professional' and 'in writing' (with 69.2% and 45.2% requesting these formats respectively). Only 12.3% indicated that they would be happy to access information via the internet and 24.0% indicated that they actively disliked this option.

MULTIVARIATE ANALYSIS OF SURVEY DATA

Relationship Between Opinions About Improvements to Services and Mental Health

Multiple regression analyses were conducted to examine the relationship between PWMCI's mental health (as measured by the SF-12v2 mental composite score (MCS)) and 'predictors' including: problem scores for desired improvements to memory clinic services items, age and sex. The multiple regression model with all predictors included produced: adjusted $R^2 = 0.14$, $F(11, 77) = 2.26$, $p < 0.02$ which suggests that, while the linear relationship between the variables is statistically significant, the scores for desired improvements to memory clinic services are a poor predictor of mental health as measured by MCS.

Relationship Between Opinions About Improvements to Services and Quality of Life

Multiple regression analyses were also conducted to examine the relationship between PWMCI's scores for the two scales in the MCQ and the 'predictors' mentioned above (i.e. problem scores for desired improvements to memory clinic services items, age and sex):

The multiple regression model for the 'emotional effects' scale, with all predictors included produced: adjusted $R^2 = 0.16$, $F(11, 82) = 2.63$, $p < 0.01$ which suggests that, while the linear relationship between the variables is statistically significant, the scores for desired improvements to memory clinic services are a poor 'predictor' of the emotional effects of living with MCI.

The multiple regression model for the 'practical concerns' scale, with all predictors included produced: adjusted $R^2 = 0.12$, $F(11, 83) = 2.21$, $p < 0.05$ which suggests that, while the linear relationship between the variables is statistically significant, the problem scores for desired improvements to memory clinic services are a poor 'predictor' of the impact of the practical effects of living with MCI.

The coefficients generated by the regression analyses described above are given in Appendix 8.

Generation of the Healthcare Experiences Summary Score

The Cronbach's alpha for using the sum of the problem scores for the items relating to 'possible improvements to memory clinic services' to produce a single 'summary' score was 0.82. This suggests that items tap an underlying or 'latent' trait.

Relationship Between Healthcare Experiences Summary Score and Experiences of Individual Aspects of Memory Clinic

Multiple regression analyses were conducted to examine the relationship between PWMCI's overall experiences of healthcare (as measured by the 'experiences of healthcare summary

score' described above) and their experiences of individual aspects of the memory clinic (using the problem scores for these items) when corrected for age and sex. The multiple regression model with all items relating to experiences of individual aspects of the memory clinic included as predictors produced: adjusted $R^2 = 0.54$, $F(11,47) = 7.21$, $p < 0.001$ which suggests that there is a statistically significant relationship between the variables and that the scores for PWMCI's experiences of individual aspects of the memory clinic are a reasonable predictor of their overall experiences of healthcare. The 'predictors' with significant regression weights were: 'feeling sufficiently involved with decisions about care' ($b=0.28$, $p<0.02$) and 'test results explained in a way you could understand' ($b = 0.29$, $p < 0.02$) which suggests that these two items contribute the most to subjects' overall experiences of healthcare. The coefficients generated by the regression analyses are given in Appendix 8.

4.3.2.2 Advocate Survey

EXPERIENCE OF CARE AT THE GENERAL PRACTITIONER

Advocates were asked why they thought the PWMCI had consulted the GP about their memory problems. The commonest reasons given were: being prompted by friends or family to do so (55.1%) or 'they went of their own accord' (37.8%).

About half the advocates surveyed (48.4%) indicated that they had been present when the linked PWMCI consulted the GP about their memory problem. The proportion of advocates reporting a problem with various aspects care when the PWMCI consulted the GP about their memory problems was calculated, these results are summarised in Table 13. The most commonly reported problems related to the issue of having to talk about the PWMCI in front of them at the GP appointment: 51.0% of advocates reported that they were not able to talk to the GP about the PWMCI in private and 22.4% reported that they found it difficult to talk about the PWMCI in front of them. Another commonly reported problem was not feeling that they had been given sufficient information by the GP (reported by 20.4% advocates).

Aspect of Care	% Indicating a Problem
GP acted quickly to get things done	6.1
Able to talk to GP about PWMCI in private	51.0
GP took PWMCI's problems seriously	2.0
Difficult to talk about PWMCI in front of them	22.4
PWMCI given right amount of time with the GP	4.1
Advocate given sufficient information	20.4
GP talked as if advocate wasn't there	4.1

Table 13. Percentage of advocates reporting a problem with aspects of care at the general practitioner in the healthcare experience survey

Subjects who indicated that they had not been present when the patient consulted the GP about their memory problems were excluded from this part of the data analysis.

EXPERIENCES OF MEMORY CLINICS

87.8% of advocates had attended memory clinic with the linked PWMCI.

The proportions of advocates reporting a problem with various aspects of care at the memory clinic are given summarised in Table 14. Some of the most commonly reported problems related to waiting times – feeling that the wait for the first clinic appointment or to receive feedback at a second appointment was too long (31.4% and 33.7% respectively). Other commonly reported problems related to the assessments used at the memory clinic: either that advocates found their part of the assessment upsetting (32.6%) or that they did not feel the tests used were appropriate for the PWMCI's memory problems (26.7%). It was also not uncommon for advocates to report having unanswered questions remaining at the end of the clinic appointment (20.9%).

Aspect of Care	% Indicating a Problem
Felt tests were appropriate for mild memory problems	26.7
Long wait for first appointment	31.4
Would have liked more than one appointment	7.0
Unanswered questions remaining	20.9
Found their part of assessment upsetting	32.6
Clinic well organised	9.3
Advocates treated with dignity and respect	2.3
PWMCI treated with dignity and respect	2.3
Results of tests explained to advocate in a comprehensible way	14.0
Wait for feedback too long	33.7

Table 14. Percentage of advocates reporting a problem with aspects of memory clinic care in the healthcare experiences survey

Subjects who indicated that they had not been present at the patient's memory clinic appointment were excluded from this part of the data analysis.

52.3% of advocates indicated that they had completed their part of the memory clinic assessments in the presence of the linked PWMCI, 97.8% of these advocates were satisfied with this arrangement. 19.8% of advocates indicated that the PWMCI had been absent during their part of the assessment, 82.4% of these advocates were satisfied with the arrangement. Again, some subjects (18.6%) answered this question in a contradictory fashion and these respondents have been excluded from this part of the data analysis (the data was treated as missing).

CURRENT SOURCES OF INFORMATION AND SUPPORT

Most advocates reported receiving practical help and emotional support either from their spouse (26.5%), other family members (44.9%) or friends (21.4%). Again, the percentage reporting that they received support from health or social care services was low (6.1%). 18.4% respondents indicated that they did not receive any help or support. A significant minority (27.6%) indicated that they did not feel they required any help or support at the

current time. However, of the advocates reporting that they did not receive any help or support only 22.2% reported that they did not feel they needed it. 9 advocates reported that they did not receive any support but simultaneously indicated sources from which they had received it – these subjects have been excluded from this part of the data analysis (the data was treated as missing).

The most commonly reported sources of information about memory problems were: the memory specialist seen by the PWMCI (59.2%), written material such as leaflets (27.6%) and the internet (21.4%). 15.3% of advocates reported that they had not received any information about MCI. 14 advocates reported that they had not received any information but simultaneously indicated sources from which they had received it – these subjects have been excluded from this part of the data analysis (the data was treated as missing).

POTENTIAL IMPROVEMENTS TO SERVICES

The proportions of advocates endorsing each of the suggested improvements to services are summarised in Table 15. The most popular suggestions for improvements to services were: provision of more information (51.2%), a shorter gap between clinic appointments (34.9%) and improved communication from the clinic (30.2%). 22.1% of respondents reported that they felt they did need extra help or support from the memory clinic.

Suggested improvement to service	% Endorsing
Offer of practical support	26.7
Different type of assessment	18.6
Improved communication from the clinic	30.2
Provision of more information	51.2
Help to talk more openly with PWMCI	25.6
Shorter gap between appointments	34.9
Better coordination of healthcare	18.6
Feels needs extra help / support from memory clinic	22.1
Feels possible for memory clinic to provide extra help / support	24.4

Table 15. Percentage of advocates endorsing suggested improvements to services in the healthcare experiences survey

Again, subjects who indicated that they had not been present at the PWMCI's memory clinic appointment were excluded from this part of the data analysis.

Aside from the question about potential improvements to services, advocates were also asked which topics they would like further information about and what format they would like to receive such information in. In response to the question about what 'further information they would like' the majority of advocates indicated that they would like more information on all the topics suggested, the most popular being: 'what they should be doing to help the PWMCI with their memory problems' (87.8%), possible treatments (86.7%) and prognosis (83.7%). Although the majority of respondents (66.3%) indicated that they would like more information about the PWMCI's test results this was the least popular suggestion and a significant minority (22.4%) reported that they actively did not want to be given more information on this topic. In response to the question about how they would like information to be provided '*provision of information by healthcare professionals in a 'face-to-face' setting*' (60.2%) or '*in writing*' (43.9%) were the most popular options, only 12.2% indicated that they would be happy to access information via the internet.

MULTIVARIATE ANALYSIS OF SURVEY DATA

Multivariate analysis was not conducted for the advocate survey data as there were a large number of respondents who were missing small amounts of data meaning that the sample

size for which complete data was available was too small for meaningful multivariate analysis to be carried out.

4.4 Discussion of Questionnaire Results

4.4.1 General

Recruitment to the 'questionnaire stage' of the study was fairly labour intensive, involving identification of potential subjects from ten research databases and memory services within seven hospital trusts. There was a relatively good response rate (54%) from people with mild cognitive impairment (PWMCI) which resulted in the recruitment target (minimum of 100 completed questionnaires) being exceeded (146 eligible subjects were recruited). Response rates were higher from potential subjects approached via research databases (59%) than memory services (33%). The fact that 88% of subjects were recruited from research databases may have introduced an element of selection bias.

The response rate from advocates was less good (advocate questionnaires were returned for 36% of the 280 advocate recruitment packs supplied to PWMCI to be passed on to advocates). Despite this, sufficient numbers of questionnaires were returned to allow the data to be analysed. The lower response rate from advocates was probably due to the fact that they were recruited via PWMCI included in the study rather than being approached directly – it is likely that quite a number of the PWMCI included either did not have a suitable advocate, did not wish to invite them to take part in the study or did not remember to do so.

That the mean age of the PWMCI in the study was 75.4 years and that there was a roughly equal split between male and female participants is reflective of the fact that the incidence and prevalence of MCI are known to increase with age but that gender is not known to be a risk factor (Luck et al., 2010a, Luck et al., 2010b, Ritchie, 2004, Feldman and Jacova, 2005). The greater age range (21 – 84 years) and lower mean age (66.3 years) of the advocates in the study reflects the fact that approximately one third were non-spousal advocates and many of these were offspring of the PWMCI. Approximately three quarters of the advocates were female and two-thirds were spouses of the PWMCI, this is in keeping with the fact that informal carers in the general population are more commonly female and that, in 60 % of carers over the age of 65, the caring responsibility is towards a spouse or partner (The NHS Information Centre, 2010). Approximately 90% of the PWMCI and advocates included in this part of the study classified themselves as 'White British' with the remainder describing themselves as 'Asian' (~5%), 'Mixed' (~1%) or 'Black' (~2%). These proportions are in keeping with the ethnic mix of the general UK population (Office of National Statistics, 2002).

Both the PWMCI and advocates included in the study appeared to have better levels of physical health (as measured by the Medical Outcomes Study Short Form health survey

(SF-12v2) Physical Health Component Score (PCS) (Ware et al., 2010)) than those of a similar age within the general population. As would be expected, SF-12v2 Mental Health Component Scores (MCS) were lower than those in the general population for both PWMCI and advocates. Although the population norms used for this comparison are based on SF-12 data from the United States of America (USA) there is evidence that, for the SF-36 at least, algorithms used in the USA and UK give very similar results (Jenkinson, 1999).

4.4.2 Patient Reported Outcome Measures

4.4.2.1 Discussion of Statistical and Technical Aspects

MILD COGNITIVE IMPIREMENT QUESTIONNAIRE (MCQ)

Certain items were removed from the MCQ due to a high proportion of respondents answering 'never'. Factor analysis of the remaining items produced two domains ('emotional effects' and 'practical concerns') each of which had high a Cronbach's alpha statistic indicating good internal consistency reliability. Indeed, the Cronbach's alpha for the emotional effects scale was 0.91 and, as this is slightly above the suggested upper cut-off of 0.9 (Cronbach, 1951, Streiner and Norman, 2003), it may suggest redundancy of items within this scale. However, as the statistic was only marginally above the upper cut-off and the domain already includes relatively few items it was decided not to attempt to further reduce the number of items in this domain.

Scores for both scales correlated well with the MCS scores for PWMCI which indicated good construct validity. This was in keeping with the hypothesis that these scales, both of which incorporate significant 'emotional' components (as items in the 'practical concerns' scale mainly relate to *worry* about the practical challenges of living with mild cognitive impairment (MCI) rather than the challenges per se) would correlate with mental health as measured by the MCS.

Finally, the high standard deviations and low percentage of respondents scoring minimum and maximum scores for each of the scales indicates that there was a good spread of data within both.

MILD COGNITIVE IMPAIRMENT QUESTIONNAIRE FOR CARERS (MCQ-CARER)

Certain items were also removed from the MCQ-Carer due to a high proportion of respondents answering 'never'. Factor analysis produced three domains ('anxiety', 'burden' and 'relationship'), the first two of which had had high Cronbach's alpha statistics indicating good internal consistency reliability. The third domain ('relationship') had a lower Cronbach's alpha of 0.67 which indicates adequate internal consistency reliability. These results are

promising in terms of the reliability of the measure, further testing on a larger sample would be helpful to confirm the reliability of all domains.

MCS scores for advocates were significantly correlated with scores on the 'anxiety' and 'relationship' scales. This was in keeping with the hypothesis that there would be the strongest relationship between advocate mental health and scores on scales with a high 'emotional' component and indicates good construct validity.

The high standard deviations and the low percentage of respondents scoring minimum and maximum scores for each of the scales indicate that there was a good spread of data within them.

4.4.2.2 Discussion of Final Versions of the MCQ and MCQ-Carer

The results discussed above indicate that the MCQ and MCQ-Carer have good psychometric properties: Internal consistency reliability is good for all but one domain (in which it is adequate) as demonstrated by the Cronbach's alpha statistics, construct validity is confirmed by the fact that there is good correlation between SF-12v2 MCS and scale scores for those scales measuring constructs related to emotion and content validity is demonstrated by the fact that the measures were developed based on the results of interviews with PWMCI and advocates.

The content of the measures reflects the varied issues which are relevant to PWMCI and their advocates: in the case of PWMCI most of these incorporate an emotional element, often pertaining to anxiety about the changes they have noticed. In the case of advocates, as well as anxiety, the scales also measure constructs relating to burden and the effect on the advocate's relationship with the PWMCI. These elements are all consistent with the 'experiences of living with / caregiving in MCI' described in the literature review in Chapter 2, although the process of factor analysis and item reduction involved in development of these measures has distilled the varied experiences described in the literature (and in the subject interviews in this study) to those which impact most on health related quality of life (HRQL) for these groups.

The MCQ and MCQ-Carer are the first outcome measures designed specifically to assess HRQL in PWMCI and their advocates. One other patient reported outcome measure (PROM), the Patient Reported Outcomes in Cognitive Impairment (PROCOG) tool (Frank et al., 2006a) has been developed for use in people with cognitive impairment but this includes both PWMCI and with mild Alzheimer's Disease (AD): the subjects interviewed in the focus groups during the initial development of the measure and those surveyed during validation of the PROCOG were comprised of roughly equal numbers of subjects with MCI and mild AD.

As discussed in the literature review in Chapter 2 it seems likely that the experiences of PWMCI and their advocates differ significantly from those in early dementia, therefore the fact that the MCQ was developed using only study subjects with a diagnosis of MCI means it is likely to be a more valid tool for assessing outcomes in this group than the PROCOG. In addition, the PROCOG has only been validated for use in the USA therefore it is unclear whether the results would be valid in a UK population. The scope of the PROCOG is much wider than the MCQ with a stated aim of '*assessing symptoms and patient rating of their impact on function, behaviour and HRQL*', as a result the tool is lengthy with 55 questions which take up to 12 minutes to complete. The purpose of the MCQ and MCQ-Carer is more focussed: to assess HRQL in PWMCI / advocates – as a result the MCQ and MCQ-Carer are much shorter (with 13 and 14 questions respectively) and less burdensome to complete (with an estimated completion time of approximately 2 minutes). Finally, although advocates were involved in the development of the PROCOG the tool is designed to measure outcomes for PWMCI only, there is no equivalent measure for advocates.

The MCQ and MCQ-Carer are short, simple assessment tools which could be used easily in variety of settings to assess the effect of interventions for these groups. At present the assessment of interventions in MCI is hampered by the lack of consensus regarding which outcome measures to use in interventional trials making the results difficult to interpret and compare (Frank et al., 2011). The MCQ and MCQ-Carer are a potential solution to this: for example, the MCQ could have a role in elucidating the effectiveness of single and multi-component support programmes, trials of which, up to now, have produced conflicting and difficult to interpret results (Joosten-Weyn Banningh et al., 2011, Lautenschlager et al., 2010), due in part to the variation in outcome measures used. In light of the United States Food and Drug Administration (FDA) (US Department of Health and Human Services et al., 2009) and European Medicines Agency (European Medicines Agency, 2005) guidance on the use of PROMs in drug trials it is also possible that the MCQ and MCQ-Carer, after appropriate further work, could play a role in the assessment of any pharmacological interventions developed for use in MCI in the future.

4.4.2.3 Interpreting the Scores of the MCQ and MCQ-Carer

Establishing the magnitude of change in scale scores which would be deemed 'clinically important' is outside the scope of this thesis. However, the following guide to the interpretation of scale scores, which is based on the Likert scale underlying each of the domains, could be used: a scale score of 0 – 20 indicates 'never' experiencing the phenomena represented by the domain, 21- 40 'rarely' experiencing them, 41 – 60 'sometimes' experiencing them, 61 – 80 'often' experiencing them and '81 – 100 'always'

experiencing them. This guide might be useful when using the MCQ or MCQ-Carer to assess outcome following an intervention, especially if the intervention resulted in a 'boundary line' between categories being crossed. The calculation of a 'standardised effect size' for each measure could also be used to guide the assessment of the effect of an intervention, this is discussed further in Chapter 5 – 'Potential Avenues for Further Work'.

4.4.3 Healthcare Experiences Survey

4.4.3.1 Discussion of Statistical and Technical Aspects

Rates of missing data were generally relatively low for most questions in the two surveys. However, some questions in the PWMCI and advocate surveys resulted in high rates of missing or contradictory data which indicates that, in any future versions of the survey, these items should be re-worded to improve readability and clarity. The questions to which this applied were: those pertaining to whether the linked patient or advocate was present during the subject's assessment at the memory clinic and the questions regarding sources of information and sources of support. In the latter two cases it was not uncommon for the respondent to select the option '*I have not received any information / support*' as well as indicating sources from which they *had* received information / support. It may be that, rather than instructing respondents to 'tick all that apply' for these questions providing 'yes'/'no' options may have produced less contradictory results.

4.4.3.2 Discussion of Results of Healthcare Experiences Survey

PEOPLE WITH MILD COGNITIVE IMPAIRMENT

Experiences of Care at the General Practitioner

The problems with care reported by PWMCI who had consulted the general practitioner (GP) about their memory problems mainly related to their lack of involvement in their care, for example reporting that they did not feel that they had been given enough information about what was happening or that they would have liked to have been more involved in decisions about their care. As mentioned previously, any guidance produced as a result of this research would be for use in memory services rather than in primary care. This is, nonetheless, useful information in that it emphasises the fact that PWMCI, despite their cognitive complaints, maintain a wish to be fully involved in their care rather than relinquishing responsibility to an advocate or 'carer' as often happens in dementia.

Experiences of Memory Clinic Services

Respondents very commonly reported that they had been concerned, prior to their memory clinic appointment, that their memory problem was of a serious nature. This is in keeping with previous studies which have shown that patients often find the time between referral to the memory clinic and the appointment a distressing time (Cahill et al., 2008). Although this is a natural concern and not one that can be eliminated, it emphasises the importance of openly acknowledging and addressing these concerns at the memory clinic. Like respondents' complaints about the care they received from their GP, additional reported problems with the memory service related to feeling insufficiently involved with their care, for example not feeling that they were given all the information they wanted and not having the results of tests explained in a way which was comprehensible to them. This is in keeping with the results of the German study of memory clinic patients which confirmed that people with mild AD and MCI do wish to be routinely involved in decisions about their care (Hamann et al., 2011). These factors should be taken into account when communicating with PWMCI in clinic. Respondents did not appear to be particularly concerned about whether their assessment took place in the presence of the advocate or separately.

Current Sources of Support

Most respondents reported receiving support from family members, very few had received support from 'formal' health or social care services. About a quarter reported that they felt that they didn't need extra support which implies that the remaining three quarters felt that they did need it. 10% of respondents indicated that they did not receive any support at all and only 50% of this group reported that they didn't feel they needed any support – implying that the other 50% felt that they needed support but weren't receiving it. Overall, these results indicate that most PWMCI report a need for help and support, that it is mostly provided by 'informal' sources and that, in a small minority, no support at all is provided despite a perceived need for it.

Current Sources of Information

The majority of subjects reported receiving information from the memory specialist they had seen; the fact that the memory service is the main source of information for PWMCI highlights the importance of providing the right information at the memory clinic appointment. One third of subjects reported receiving information about their condition from friends and family, this emphasises the importance of ensuring that advocates are provided with high quality information about MCI as it seems that many PWMCI turn to them for information they may not have requested at the clinic or been able to recall subsequently. Only slightly more than a quarter of the respondents reported receiving information via written material such as leaflets, something which may reflect the relative shortage of information leaflets on

this topic, as discussed in the literature review in Chapter 2. Less than 10% of respondents had obtained information about MCI from the internet. A recent study of internet usage in older people attending a urology outpatient clinic showed relatively low rates of internet usage in older patients: 59% of the patients in the 70 -79 year age group had access to the internet at home (compared to 100% in the 30-39 year age group) but 42% reported they had never used the internet (Macfarlane et al., 2012). The very low rates of internet usage reported by the PWMCI in the study are likely to be a reflection of their age, their cognitive difficulties (which may interfere with the skills required to use the internet) and possibly uncertainty about where to look on the internet for reliable information about health.

Suggested Improvements to Memory Services

INFORMATION PROVISION

About 40% of respondents reported that they would have liked to have been given more information at the memory clinic appointment, while this is a significant minority it is worth noting that less than half of respondents responded in the affirmative to this general question about information provision. However, when asked whether they would like more information on *specific* topics the majority of subjects indicated that they did want more information on almost all topics listed (with between 76% and 93% endorsing the various subjects suggested) i.e. 'possible treatments for your memory problems', 'tips on how to get around memory problems', 'what you can do to prevent your memory problems getting any worse', 'the causes of your memory problems' and 'whether your memory problems are likely to get worse over time'. This is likely explained by the fact that patients may not be aware of areas of potential information until they are presented with them. Dissatisfaction with information provision at memory clinic appointments has been identified in other studies, such as the Dutch survey of memory clinic patients in which only ~40% were satisfied with the clarity of the information which they had been given (van Hout et al., 2001).

A notable exception to the positive responses regarding information provision was the response to the question 'would you like more information on...the results of tests you have had?', with only 58.2% of respondents answering 'yes' to this question (and 24.7% actively indicating that they did not want to be given this information). This suggests that PWMCI may fall into two groups: those who wish to be given detailed information about their test results (as was the case for several of the interview subjects in the first part of the study) and those who do not. It is recognised that there are two distinct coping styles in terms of information-seeking in response to a 'health threat': 'monitoring' (i.e. seeking and paying close attention to information about the threat) and 'blunting' (i.e. avoiding information about the threat') (Case et al., 2005). It seems likely that the degree of information a patient seeks

about their test results, which have a particularly high potential to represent a threat to health, would be heavily influenced by their coping style. Therefore, a sensible approach in clinical practice would be to ask PWMCI how much detail regarding their test results they would like to be given so that information on this topic may be tailored accordingly.

The majority of respondents indicated that they wanted information to be provided '*face-to-face*', *by a healthcare professional*' and just under half endorsed information being given '*in a written format e.g. letter or leaflet*'. It seems likely that a combination of these two methods of information provision would be the most effective, especially as it is known that patients do not retain all of the information given to them by healthcare professionals, with studies suggesting that between 40 and 80% of the information given is forgotten immediately and that almost 50% of the information which is remembered is incorrect (Kessels, 2003). It has been shown that written information is remembered better by patients (Blinder et al., 2001) and of course it can be referred to again at a later date. For this reason the provision of written information to PWMCI, who are likely to have even greater difficulty with recalling information given during a consultation than the general population, is particularly important. Many of the subjects in Cahill's study of memory clinic users expressed a preference for a combination of verbal and written information (Cahill et al., 2008). Provision of information via the internet was not a popular option, probably due to the reasons discussed earlier. However, this finding should not necessarily completely preclude the use of the internet for this purpose as it may be that future generations of PWMCI, who are more familiar with the use of the internet to access information, would be more amenable to obtaining information in this way.

TESTS USED IN CLINIC

Respondents commonly reported that they '*would like to have been assessed using tests that seemed more appropriate to the nature of their memory problems*'. This is a concept which was mentioned by several of the interview subjects in the first part of the study, who felt that many of the tests used in the memory clinic appeared to be geared towards people with more severe cognitive problems such as dementia and did not take prior educational level or intellect into account. In the questionnaire stage of the study, information about which assessments the study subjects had undergone in clinic was not available. However, this information was available for many of the participants in the interview stage of the study (whose clinical notes were reviewed as part of the screening process); the majority had been assessed using commonly employed cognitive tests such as the Mini-Mental State Examination (MMSE) (Folstein et al., 1975), the Montreal Cognitive Assessment (MoCA) (Nasreddine et al., 2005) and the CLOX test (Royall et al., 1998). The MoCA was developed

as a screening tool for MCI as to this end does have a high sensitivity (90%) and specificity (87%) for this purpose (Nasreddine et al., 2005). Despite the fact that the MMSE is probably the most widely used cognitive screening tool in primary and secondary care in the UK its value in the detection of MCI remains uncertain; a pooled meta-analysis conducted in 2009 estimated that it had a sensitivity of just 63% and specificity of 65% for distinguishing MCI from normal cognition (Mitchell, 2009). Evidence for the use of the CLOX test in screening for MCI is mixed but most studies suggest that it too has poor sensitivity and specificity for the detection of MCI (Forti et al., 2010, Ehreke et al., 2010, Lee et al., 2008b). In light of this, those PWMCI assessed using the MMSE and CLOX test were technically correct in their impression that tests they completed were more appropriate for people with dementia, but it should not be forgotten that clinicians in memory clinics are looking to diagnose or exclude a range of conditions, including dementia, and therefore the application of these tests at a first clinic appointment will very often be appropriate. Therefore it may be that, rather than changing the tests that are used in clinic, a clear explanation of the purpose of the tests should be given, including reassurance that performance on the CLOX test appears to be independent of educational level (Royall et al., 1998) and that scores on the MMSE (Crum et al., 1993) and MoCA (Johns, 2008) can be corrected to take education into account.

OTHER SUGGESTED CHANGES

About one third of respondents stated that they ‘would have liked more warning of what was going to happen at the assessment’, this is something which could be addressed fairly easily by provision of information in the letter which is sent to patients informing them of the date and location of their appointment.

While about a quarter of respondents indicated that they *didn’t* feel they needed any help or support in response to the question about sources of support (implying that the remaining three quarters felt that they *did* need help or support) only one fifth of respondents reported that they felt that did need ‘*extra help or support from the memory clinic at the moment*’. This discrepancy is most likely due to patients feeling that they do need extra help and support but not that it should necessarily be provided by the memory clinic. In light of this it may be helpful to use ‘signposting’ to direct PWMCI to alternative sources of information and support e.g. ‘dementia advisor’ equivalents and voluntary organisations. Recommendations about the types of additional support which would be helpful for PWMCI are beyond the scope of this study, whose focus is issues directly relevant to PWMCI’s contact with healthcare services, but these are briefly discussed in the literature review in Chapter 2.

Summary Measures of Experience

Multivariate analysis of the survey data revealed no significant relationship between respondents' opinions about possible improvements to healthcare services and scores on the MCS or MCQ scales. This suggests that opinions about improvements to healthcare cannot be used as a reliable surrogate marker of the PWMCI's overall experience of living with MCI, possibly due to the effect of difficulties with recall of the details of the clinic appointment. However, it was shown that individual aspects of respondents' experiences at memory clinic did correlate well with their overall experience of healthcare (as measured by the 'healthcare experience summary score', calculated from the sum of the problem scores for 'possible improvements to services'). The items contributing the most to overall experience were 'feeling sufficiently involved with decisions about care' and 'test results explained in a way you could understand', this is in keeping with the finding from the initial analysis of the survey data.

ADVOCATES

Experiences of Care at the General Practitioner

The problems reported most commonly by advocates who had been present when the PWMCI consulted the GP related to having to discuss their concerns in front of the PWMCI, with half reporting that they were not able to talk to the GP in private and one fifth that they found it difficult to talk about the PWMCI in front of them. Advocates also commonly reported not feeling that they themselves had been given sufficient information by the GP. Again, guidance for GPs coming into contact with the advocates of PWMCI is outside the scope of this thesis, but this remains important information that should be borne in mind when providing support to advocates.

Experiences of Memory Clinic Services

The problems with memory clinic most commonly reported by advocates related to waiting times for either a first or second appointment, which they generally felt were too long. Information about the time from referral to first clinic appointment / time between appointments was not collected, therefore unfortunately it is not possible to comment on how long the actual waiting times were and hence what period of time the respondents deemed 'too long' to wait.

Problems regarding the assessments used in clinic were also commonly reported: About a quarter of advocates reported '*not feeling that tests were appropriate for the PWMCI's mild memory problems*'. This is a similar concept to that expressed by the subjects with MCI who indicated that they '*would like to have been assessed using tests that seemed more*

appropriate to the nature of their memory problems'. Another common problem was advocates *'finding their part of the assessment, such as having to 'report on' (the PWMCI), upsetting'*. Although it might be hypothesised that part of the reason for advocates finding their part of the tests upsetting could relate to having to 'report on' the PWMCI in front of them it does not appear that the majority of advocates objected to completing their part of the assessment in the PWMCI's presence: Advocates were asked about whether they had completed their part of the assessments at the memory clinic in the presence of the PWMCI or separately and how satisfied they were with this arrangement. Advocates more commonly reported completing their part of the assessments in the presence of the PWMCI than separately but the vast majority in both groups were satisfied with the 'set-up' for the assessment, therefore there does not seem to be a compelling reason to recommend a change in clinical practice either towards or away from joint assessments. It seems likely that the best solution to dissatisfaction with the tests used in clinic lies in a very clear explanation of their purpose, which is given to the advocate as well as the PWMCI, bearing in mind that this may need to be repeated if the PWMCI is not present during the initial explanation. Information about which tests the advocates taking part in the survey had felt were particularly inappropriate was not available. However, from the descriptions given by some of the advocates in the interview stage of the study it seems that, as well as feeling that the cognitive tests used to assess the PWMCI were too simple, many advocates had been asked to complete a Bristol Activities of Daily Living Scale (BADLS) (Bucks et al., 1996) for the PWMCI which they felt was inappropriate for their current level of functioning. The BADLS was developed as a tool to assess function at baseline, and its change over time, in people with dementia and it is well validated for this purpose. Although it is commonly used for the assessment of function in PWMCI it has not been validated for use in this group and therefore the advocates reporting that they did not feel that the tests used were appropriate were technically correct in cases where the BADLS had been used.

Finally, in keeping with the theme of insufficient information provision which has emerged thus far, about a fifth of advocates stated that they had unanswered questions remaining following their clinic appointment.

Current Sources of Support

The majority of advocates reported receiving help and support from friends and family members, with very few (only just over 5%) reporting the use of formal services. About one quarter of respondents indicated that they felt they didn't need any help or support – implying that the remaining three quarters felt that they did need it. Approximately a fifth of advocates reported not receiving any help and again, about three quarters of this group indicated that

they felt they did need it. The fact that a significant minority of advocates reported not wanting any support is in keeping with the findings of Adams' study of caregivers in MCI which identified ambivalence about seeking formal and informal support in some carers, often due to feeling that it was 'too early' to do so or that it would place undue burden on family members (Adams, 2006). Overall, our findings indicate that the vast majority of advocates feel that they need help and support and that, worryingly, there is a significant minority who, despite feeling that they need this assistance, do not receive it.

Current Sources of Information

Like the PWMCI surveyed, the advocates most commonly obtained information from the memory specialist seen by the PWMCI. Although this group had obtained information about MCI from the internet more commonly than the respondents with MCI this remained a relatively unpopular source of information, used by only one fifth of advocates. As discussed for the PWMCI, this is likely to be a reflection of the older age group into which the majority of advocates fell. A significant minority reported receiving no information about MCI.

Suggested Improvements to Memory Services

INFORMATION PROVISION

The most popular suggested improvement to the memory service was the provision of more information – with just over half of all advocates endorsing this option. An even greater proportion of respondents (between 68% and 88%) indicated that they would like more information on the individual topics suggested i.e. *'whether the PWMCI's problems are likely to get worse over time'*, *possible treatments for the PWMCI's memory problems'*, *'what I should be doing to help the PWMCI with their memory problems'* and *'other health problems that the PWMCI has that might affect their memory'*. The fact that the majority of advocates wanted to be provided with more information about MCI is in keeping with the findings and recommendations of other studies in the area (Lu and Haase, 2009, Joosten-Weyn Banningh et al., 2008, Adams, 2006, Kuo and Shyu, 2010). The desire for information specifically about what the advocate *'should be doing to help the PWMCI with their memory problems'* expressed by advocates in this study tallies with the recommendations from several other studies that advocates should be provided with strategies to assist the PWMCI in everyday life (Blieszner and Roberto, 2010, Austrom and Lu, 2009, Lu et al., 2007a, Roberto et al., 2011).

Also reflecting the findings from the PWMCI healthcare experiences survey was the fact that the least popular suggested information topic for advocates was 'the results of tests taken by your relative/ friend', with only 66% endorsing this option. Again, this may be due to

differences in coping strategies used by different advocates and therefore a tailored approach to information provision on this topic would be sensible. Advocates reported that they would like information to be provided 'face-to-face by a healthcare professional' or 'in written form e.g. a letter or a leaflet' and, despite the fact that more advocates than PWMCI had already used the internet to search for information on MCI, it was an unpopular choice for the provision of further information with only just over 10% advocates indicating that they would choose this medium. Again, this is something that may change as future generations move into caring roles and become advocates.

COMMUNICATION

Another commonly endorsed suggestion was that '*communication from the clinic could have been improved*' which reflects the views expressed by many of the advocates interviewed in the first stage of the study who felt that, following the clinic appointment, they had been 'left in the dark' about the outcome of the assessments and plans for follow up. Improvements in information provision at the clinic appointment, as described above and the inclusion of details of any plans for follow up, should go some way to addressing this issue. Provision of a written summary of the outcome of the appointment and follow-up plans would also be useful, particularly in light of advocates' expressed preference for written information; it might also address some advocates' concerns about the length of wait for feedback during a follow-up appointment. It may be that ensuring that the advocate (with the consent of the PWMCI) receives a copy of the clinic letter which is sent to the GP would be a convenient way of improving communication without creating excessive additional paperwork. This is in keeping with Department of Health Guidance on the topic which recommends that, where possible and appropriate, clinic letters should be copied to patients and, if the patient gives consent, to carers (Department of Health, 2003). Studies have suggested that patients, including those attending psychiatry clinics, generally have positive attitudes about receiving a copy of the clinic letter (Imtiaz et al., 2012, Tahir et al., 2005) and that the practice may result in patients feeling more involved in their care (Williams and Kelsey, 2009). Unfortunately no studies have examined the effect of sending copies of clinic letters to carers of people with cognitive problems.

INTERVAL BETWEEN APPOINTMENTS

About a third of advocates stated that they would have liked a shorter gap between the PWMCI's clinic appointments. Information on the interval between appointments for the PWMCI included in the study was not available but follow up for this group is usually provided at intervals of between 6 months and 1 year. More frequent follow up than this may not be feasible within the confines of the National Health Service (NHS) nor is it likely to be

particularly clinically useful as it is unlikely that significant cognitive changes would be detectable in a PWMCI after an interval of less than 6 months, even when MCI is due to the pre-dementia phase of Alzheimer's disease.

Therefore, rather than altering the follow-up interval, a more helpful strategy may be to include in the information provided to the advocate a careful explanation of when the next appointment is likely to be, the reason for the time period between appointments and the details of who they can contact (e.g. the GP or a member of the memory clinic staff) should they have significant concerns about changes in the PWMCI's cognition before the next scheduled appointment. Brief telephone contact with advocates between clinic appointments might also be helpful to address some of the concerns which cause advocates to seek more frequent follow up.

OTHER SUGGESTED CHANGES

The other commonly endorsed suggested improvements were '*help for the advocate to talk more openly to the PWMCI about their memory problems*' and '*being offered practical support e.g. home help or a support group*'. The first of these could be addressed briefly in the clinic and information on sources of practical and emotional support (including, where required, counselling to facilitate communication within PWMCI-advocate dyads) could also be offered. Again, it is beyond the scope of this study to recommend which forms of additional support are most appropriate but those commonly suggested by other authors (such as psychosocial training and support groups) are discussed in the literature review in Chapter 2.

Similar to the PWMCI surveyed there was a discrepancy between the proportion of advocates who reported that they felt they needed help (~75%, as discussed above) and the proportion who reported feeling that they needed *extra* help or support *from the memory clinic* (only about 20%). The reasons for this difference are likely to be similar to those discussed for PWMCI. The hypothesis that advocates do not feel that the memory clinic is the source from which they should be receiving help or support is supported by the fact that only a quarter of advocates indicated that they felt it was possible for the memory clinic to provide them with help or support at the current time. Again, 'signposting' alternative sources of support and information may be helpful for advocates.

4.5 Summary

The two outcome measures developed – the MCQ and the MCQ-Carer – have good psychometric properties and are potentially useful tools for measuring HRQL in PWMCI and

their advocates. The 'experiences of healthcare surveys' identified several areas in which the experiences of these groups might be improved: provision of information about various aspects of MCI, 'signposting' regarding appropriate sources of help and support, careful explanation of the tests used during clinical assessment and, for advocates, ensuring that communication from the clinic is effective.

Chapter 5 – Conclusion

5.1 Summary of Findings

The interview stage of the study provided in-depth information about the experiences of people with mild cognitive impairment (PWMCI) and their advocates, both about daily life with mild cognitive impairment (MCI) and about their experiences of healthcare services. Both groups described a range of cognitive changes and resulting functional limitations in the PWMCI. Negative emotional consequences were also commonly reported – but not infrequently there was a discrepancy between the degree of distress reported by the PWMCI and the advocate (in whom it was usually greater). Attributions were varied in both groups but PWMCI most commonly ascribed their symptoms to ‘normal ageing’ whereas, in general, advocates were more uncertain as to the cause, often blaming physical health problems. In describing their experiences of healthcare services the advocates interviewed more commonly reported negative impressions than the PWMCI who more frequently described the encounters in a neutral or even positive way. Both groups reported receiving little information or formal support from health or social care services, although advocates reported being more distressed by this than the PWMCI interviewed. In keeping with these findings many PWMCI reported that they did not think any changes to healthcare services were necessary whereas most advocates had suggestions for improvements to services. Where changes were suggested these most commonly (for both groups) related to increasing the amount of information provided about MCI and related topics. These findings indicate that MCI represents a disease state which is often already having a clinical impact and are in also keeping with the concept of MCI as part of ‘pre-dementia Alzheimer’s disease’, as per the new diagnostic criteria (Albert et al., 2011).

The questionnaire stage of the study provided data for two purposes: The first was the development of a patient reported outcome measure (PROM) for PWMCI and an equivalent measure for advocates. The data from the ‘quality of life’ section of the questionnaire was analysed using factor analysis and the two measures – the Mild Cognitive Impairment Questionnaire (MCQ) and the Mild Cognitive Impairment Questionnaire for Carers (MCQ-Carer) - were produced (see Appendices 6 and 7). Both were found to have good psychometric properties. The second purpose of the questionnaire was to allow exploration of the issues relating to experiences of healthcare services, as identified in the interview stage of the study, in a larger sample. Analysis of the data from the ‘healthcare experiences’ sections of the questionnaires revealed that both PWMCI and advocates reported unmet needs for support and information: The PWCMI surveyed reported that their main concern

relating to the memory clinic appointment was worry, before the appointment, that their memory problems were due to a serious condition. Other complaints related to feeling insufficiently involved with their care at the clinic e.g. not being given all the information they wanted or their test results not being explained in a way they could understand. PWMCI most commonly reported receiving information about their condition from the memory specialist they had seen or from friends and family. Most reported wanting more information on a variety of topics (with the exception of additional information about their test results, about which opinion was divided) provided either 'face-to-face' by a health care professional and / or in writing. The majority of the PWMCI surveyed felt they needed help and support because of their MCI; very few reported receiving formal support from health or social care services, most received it from friends or family (and 10% reported not receiving any help or support at all). However, despite reporting this need for help and support most respondents indicated that they did not necessarily expect this to be provided by the memory clinic. Other improvements to services endorsed by PWMCI included the use of tests that seemed 'more appropriate' for their mild memory problems and being given more warning of what to expect at the clinic appointment.

The concerns about memory clinic most commonly reported by the advocates surveyed related to the length of time the PWMCI had waited either for their first clinic appointment or for a follow-up appointment. Other common concerns related to the assessments used in clinic: either that they did not seem appropriate for the PWMCI's mild memory problems or that they found the part of the assessment they took part in upsetting. A significant minority of advocates reported that they had unanswered questions remaining following the memory clinic appointment. Suggested improvements to the memory service that advocates frequently endorsed were: improved communication from the memory clinic, a shorter interval before or between clinic appointments and being offered practical support or help to talk more openly with the PWMCI about their memory problems. Like the PWMCI surveyed, the majority of advocates reported feeling that they needed help and support because of the PWMCI's memory problems, although not that it should necessarily be provided by the memory clinic. Most advocates reported receiving support from friends or family, very few had accessed 'formal' health or social care support and 20% reported receiving no help or support at all. Also reflecting the findings from the PWMCI survey, the majority of advocates reported receiving information about MCI from the memory specialist seen in clinic and most wanted more information on all topics suggested, once again with the exception of the PWMCI's test results, about which opinion was divided. Advocates also wanted information to be provided either face-to-face or in writing.

5.2 Potential Avenues for Future Work

5.2.1 Further Development of the MCQ and MCQ-Carer

There are several potential avenues for further work involving the MCQ and MCQ-Carer: As mentioned in the section on 'Discussion of Questionnaire Results' in Chapter 4, further testing of both measures in a larger sample would be helpful to confirm the internal consistency reliability of all their domains. Given the fact that cognitive problems affect people in all countries the translation of the measures into languages other than English and validation for use in these languages would increase the scope for their use. Indeed, it would be helpful to explore many of the issues discussed in this thesis both in other countries and within ethnic minority groups in the UK. As healthcare services are moving progressively towards the use of electronic patient records, adaptation of the measures for use in an electronic format, together with validation for use in this modality, would be useful.

As discussed in the section 'Interpreting the Scores of the MCQ and MCQ-Carer' in Chapter 4, the calculation of standardised effect sizes for the measures would be helpful if they are to be used for assessing outcomes following an intervention. However, this approach does not necessarily reflect the operating characteristics of an individual measure and therefore, in line with the US Food and Drug Agency (FDA) guidance on the topic, further work to establish the responsiveness of the MCQ and MCQ-Carer (via a sensitivity to change analysis) would be preferable to facilitate the use of the measures in assessing interventions.

5.2.2 Guidance for Memory Services

The findings regarding PWMCI and advocates' experiences of healthcare services, as described in this thesis and summarised above, could potentially be used to develop guidelines for use by memory services when managing PWMCI and their advocates. The only published 'support programme' designed specifically for PWMCI is Lu and Haase's 'Daily Enhancement of Meaningful Activity' (DEMA) programme (Lu and Haase, 2011) which is described in the literature review in Chapter 2. Although this programme does include elements which reflect the findings of this study, for example an emphasis on information provision to the PWMCI and their advocate, its focus is on the provision of support *after* the diagnosis of MCI is made rather than during the process of assessment and diagnosis within healthcare services. Aside from those relating to purely clinical aspects, such as appropriate investigations and pharmacological therapies, no published guidelines regarding other aspects of the management of PWMCI and their advocates within healthcare services were identified by the literature review described in Chapter 2.

The data in this study was collected in such a way that it is valid for use at an aggregate, rather than individual level. Therefore any guideline developed based on this data would require further evaluation before it could be used within clinical practice. Nonetheless, the following suggestions represent a potential starting point for improving the experiences of PWMCI and their advocates with healthcare services:

Guidance for the management of PWMCI could cover areas such as:

- Provision of information in the clinic booking letter about what will happen at the appointment
- Open acknowledgment of concerns about the nature of the PWMCI's memory problems
- Provision of a clear explanation of the cognitive tests that are to be used
- Provision of appropriate verbal and written information on the topics discussed in this thesis
- Ensuring that the PWMCI feels sufficiently involved with decisions being made about their care
- Use of 'signposting' to direct PWMCI to alternatives to the memory clinic for information and support

Guidance for the management of advocates of PWMCI could cover areas such as:

- Provision of a clear explanation of the cognitive tests that are to be used for the PWMCI and any assessments that are to be completed by the advocate.
- Provision of information on the topics discussed in this thesis, both verbally and in writing
- Facilitation of communication between the PWMCI and advocate regarding the memory problems
- Use of 'signposting' to direct advocates to alternatives to the memory clinic for information and support

5.3 Conclusion

As per the aim of this study, information about the experiences of PWMCI and their advocates, with particular reference to their involvement with healthcare services has been gathered – both from in-depth interviews and surveys of a larger sample. The findings confirm some of those from the existing literature in this area regarding the challenges faced by PWMCI and their advocates in daily life and they also shed new light on issues specific to contact with healthcare services for these groups. The information gathered was used to

develop a PROM to assess health related quality of life in PWMCI (the MCQ) and an equivalent measure for advocates (the MCQ-Carer); both have good psychometric properties and therefore have the potential for use to assess outcomes in these groups within clinical practice. A detailed picture of the experiences of PWMCI and their advocates within healthcare services was obtained and, on the basis of this, suggestions for improvements to services have been made. It is hoped that the findings described here will improve the experiences of these, up to now somewhat neglected, groups within healthcare services.

Bibliography

- ABBATE, C., TRIMARCHI, P. D., NICOLINI, P., BERGAMASCHINI, L., VERGANI, C. & MARI, D. 2011. Comparison of informant reports and neuropsychological assessment in mild cognitive impairment. *Am J Alzheimers Dis Other Dement*, 26, 528-34.
- ADAMS, K. B. 2006. The transition to caregiving: the experience of family members embarking on the dementia caregiving career. *Journal of Gerontological Social Work*, 47, 3-29.
- AHN, I. S., KIM, J. H., KIM, S., CHUNG, J. W., KIM, H., KANG, H. S. & KIM, D. K. 2009. Impairment of instrumental activities of daily living in patients with mild cognitive impairment. *Psychiatry Investig*, 6, 180-4.
- ALBERT, M. S., DEKOSKY, S. T., DICKSON, D., DUBOIS, B., FELDMAN, H. H., FOX, N. C., GAMST, A., HOLTZMAN, D. M., JAGUST, W. J., PETERSEN, R. C., SNYDER, P. J., CARRILLO, M. C., THIES, B. & PHELPS, C. H. 2011. The diagnosis of mild cognitive impairment due to Alzheimer's disease: recommendations from the National Institute on Aging-Alzheimer's Association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement*, 7, 270-9.
- ALZHEIMER'S DISEASE INTERNATIONAL 2011. World Alzheimer Report 2011. The benefits of early diagnosis and intervention.
- ALZHEIMER'S SOCIETY 2005. Factsheet (470) Mild Cognitive Impairment. .
- ANSTEY, K. J., CHERBUIN, N., CHRISTENSEN, H., BURNS, R., REGLADE-MESLIN, C., SALIM, A., KUMAR, R., JORM, A. F. & SACHDEV, P. 2008. Follow-up of mild cognitive impairment and related disorders over four years in adults in their sixties: the PATH Through Life Study. *Dementia and Geriatric Cognitive Disorders*, 26, 226-33.
- ARTERO, S., TOUCHON, J. & RITCHIE, K. 2001. Disability and mild cognitive impairment: a longitudinal population-based study. *International Journal of Geriatric Psychiatry*, 16, 1092-7.
- AUSTROM, M. G. & LU, Y. 2009. Long term caregiving: helping families of persons with mild cognitive impairment cope. *Current Alzheimer Research*, 6, 392-8.
- BARRETT, P. T. & KLINE, P. 1981. The observation to variable ratio in factor analysis. *Personality Study in Group Behavior*, 1, 23-33.
- BEARD, R. L. & NEARY, T. M. 2012. Making sense of nonsense: experiences of mild cognitive impairment. *Sociol Health Illn*, 35, 130-46.
- BEGUM, A., MORGAN, C., CHIU, C. C., TYLEE, A. & STEWART, R. 2012. Subjective memory impairment in older adults: aetiology, salience and help seeking. *Int J Geriatr Psychiatry*, 27, 612-20.
- BERWIG, M., LEICHT, H. & GERTZ, H. J. 2009. Critical evaluation of self-rated quality of life in mild cognitive impairment and Alzheimer's disease--further evidence for the impact of anosognosia and global cognitive impairment. *J Nutr Health Aging*, 13, 226-30.
- BLIESZNER, R., ROBERTO, A., WILCOX, L., BARHAM, J. & WINSTON, L. 2007. Dimensions of Ambiguous Loss in Couples Coping With Mild Cognitive Impairment. *Family Relations: An Interdisciplinary Journal of Applied Family Studies*, 56, 196-209.
- BLIESZNER, R. & ROBERTO, K. A. 2010. Care partner responses to the onset of mild cognitive impairment. *Gerontologist*, 50, 11-22.
- BLINDER, D., ROTENBERG, L., PELEG, M. & TAICHER, S. 2001. Patient compliance to instructions after oral surgical procedures. *International journal of oral and maxillofacial surgery*, 30, 216-9.
- BOISSONNEAULT, G. A. 2010. MCI and dementia: diagnosis and treatment. *JAAPA*, 23, 18, 21-2.

- BROD, M., STEWART, A. L., SANDS, L. & WALTON, P. 1999. Conceptualization and measurement of quality of life in dementia: the dementia quality of life instrument (DQoL). *Gerontologist*, 39, 25-35.
- BROWN, P. J., DEVANAND, D. P., LIU, X. & CACCAPPOLO, E. 2011. Functional Impairment in Elderly Patients With Mild Cognitive Impairment and Mild Alzheimer Disease. *Archives of General Psychiatry*, 68, 617-626.
- BRUCE, J. M., MCQUIGGAN, M., WILLIAMS, V., WESTERVELT, H. & TREMONT, G. 2008. Burden among spousal and child caregivers of patients with mild cognitive impairment. *Dementia and Geriatric Cognitive Disorders*, 25, 385-90.
- BUCKS, R. S., ASHWORTH, D. L., WILCOCK, G. K. & SIEGFRIED, K. 1996. Assessment of activities of daily living in dementia: development of the Bristol Activities of Daily Living Scale. *Age and ageing*, 25, 113-20.
- BURNS, A. 2012. The benefits of early diagnosis of dementia. *BMJ*, 344, e3556.
- BURNS, A. & RABINS, P. 2000. Carer burden dementia. *International Journal of Geriatric Psychiatry*, 15 Suppl 1, S9-13.
- CAHILL, S. M., GIBB, M., BRUCE, I., HEADON, M. & DRURY, M. 2008. 'I was worried coming in because I don't really know why it was arranged'. *Dementia*, 7, 175-189.
- CARPENTER, B. D., XIONG, C., PORENSKY, E. K., LEE, M. M., BROWN, P. J., COATS, M., JOHNSON, D. & MORRIS, J. C. 2008. Reaction to a dementia diagnosis in individuals with Alzheimer's disease and mild cognitive impairment. *J Am Geriatr Soc*, 56, 405-12.
- CASE, D. O., ANDREWS, J. E., JOHNSON, J. D. & ALLARD, S. L. 2005. Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *Journal of the Medical Library Association : JMLA*, 93, 353-362.
- CHEN, P. H., GOLUB, J. S., HAPNER, E. R. & JOHNS, M. M., 3RD 2009. Prevalence of perceived dysphagia and quality-of-life impairment in a geriatric population. *Dysphagia*, 24, 1-6.
- CHERTKOW, H., MASSOUD, F., NASREDDINE, Z., BELLEVILLE, S., JOANETTE, Y., BOCTI, C., DROLET, V., KIRK, J., FREEDMAN, M. & BERGMAN, H. 2008. Diagnosis and treatment of dementia: 3. Mild cognitive impairment and cognitive impairment without dementia. *Canadian Medical Association Journal*, 178, 1273-85.
- COSTELLO, A. B. & OSBORNE, J. W. 2005. Best Practices in Exploratory Factor Analysis: Four Recommendations for Getting the Most From Your Analysis. *Practical Assessment, Research and Evaluation*, 10.
- CRONBACH, L. 1951. Coefficient alpha and the internal structure of tests. *Psychometrika*, 16, 297-334.
- CRUM, R. M., ANTHONY, J. C., BASSETT, S. S. & FOLSTEIN, M. F. 1993. Population-based norms for the Mini-Mental State Examination by age and educational level. *JAMA : the journal of the American Medical Association*, 269, 2386-91.
- DE VRIENDT, P., GORUS, E., CORNELIS, E., VELGHE, A., PETROVIC, M. & METS, T. 2012. The process of decline in advanced activities of daily living: a qualitative explorative study in mild cognitive impairment. *Int Psychogeriatr*, 24, 974-86.
- DENIZARD-THOMPSON, M., FEIEREISEL, B., STEVENS, F., MILLER, P. & WOFFORD, L. 2011. The digital divide at an urban community health center: Implications for quality improvement and health care access. *Journal of Community Health: The Publication for Health Promotion and Disease Prevention*, 36, 456-460.
- DEPARTMENT OF HEALTH 2003. Copying Letters to Patients: Good Practice Guidelines.
- DEPARTMENT OF HEALTH 2009a. Guidance on the Routine Collection of Patient Reported Outcome Measures (PROMs).
- DEPARTMENT OF HEALTH 2009b. Living Well with Dementia: a National Dementia Strategy.
- DEPARTMENT OF HEALTH 2010. Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy.
- DEPARTMENT OF HEALTH 2012. Prime Minister's challenge on dementia.

- DEPARTMENT OF HEALTH & MEDICAL RESEARCH COUNCIL 2009. Report from the Ministerial Summit on Dementia Research.
- DEPARTMENT OF HEALTH (ENGLAND) 2011. Press release: Six out of ten people with dementia go undiagnosed – £2 million campaign launched to tackle dementia.
- DERKSEN, E., GRAFF, M., VISSER, P.-J., VERNOOIJ-DASSEN, M. & OLDE RIKKERT, M. 2009. MCI-patients': worries about their prognosis justified? *Journal of Neurology, Neurosurgery and Psychiatry with Practical Neurology* [Online]. Available: <http://jnnp.bmj.com/letters/?first-index=76&hits=60> [Accessed 31/03/2011].
- EHREKE, L., LUPPA, M., KONIG, H. H. & RIEDEL-HELLER, S. G. 2010. Is the Clock Drawing Test a screening tool for the diagnosis of mild cognitive impairment? A systematic review. *International psychogeriatrics / IPA*, 22, 56-63.
- EUROPEAN MEDICINES AGENCY 2005. Reflection Paper on the Regulatory Guidance for the Use of Health Related Quality of Life (HRQL) Measures in the Evaluation of Medicinal Products.
- FARIAS, S. T., MUNGAS, D. & JAGUST, W. 2005. Degree of discrepancy between self and other-reported everyday functioning by cognitive status: dementia, mild cognitive impairment, and healthy elders. *International Journal of Geriatric Psychiatry*, 20, 827-34.
- FARIAS, S. T., MUNGAS, D., REED, B. R., HARVEY, D. & DECARLI, C. 2009. Progression of mild cognitive impairment to dementia in clinic- vs community-based cohorts. *Arch Neurol*, 66, 1151-7.
- FAYERS, P. M. & MACHIN, D. 2000. *Quality of Life - Assessment, Analysis and Interpretation*, Chichester, Wiley.
- FELDMAN, H., SCHELTENS, P., SCARPINI, E., HERMANN, N., MESENBRINK, P., MANCIONE, L., TEKIN, S., LANE, R. & FERRIS, S. 2004. Behavioral symptoms in mild cognitive impairment. *Neurology*, 62, 1199-201.
- FELDMAN, H. H. & JACOVA, C. 2005. Mild cognitive impairment. *Am J Geriatr Psychiatry*, 13, 645-55.
- FOLSTEIN, M. F., FOLSTEIN, S. E. & MCHUGH, P. R. 1975. "Mini-mental state": A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- FORTI, P., OLIVELLI, V., RIETTI, E., MALTONI, B. & RAVAGLIA, G. 2010. Diagnostic performance of an Executive Clock Drawing Task (CLOX) as a screening test for mild cognitive impairment in elderly persons with cognitive complaints. *Dementia and Geriatric Cognitive Disorders*, 30, 20-7.
- FRANK, B. 2007. Commentary on "Health economics and the value of therapy in Alzheimer's disease." Report from the Alzheimer's Association Research Roundtable on patient-reported outcomes and dementia research. *Alzheimer's & Dementia*, 3, 162-165.
- FRANK, L., FLYNN, J. A., KLEINMAN, L., MARGOLIS, M. K., MATZA, L. S., BECK, C. & BOWMAN, L. 2006a. Validation of a new symptom impact questionnaire for mild to moderate cognitive impairment. *Int Psychogeriatr*, 18, 135-49.
- FRANK, L., LENDERKING, W. R., HOWARD, K. & CANTILLON, M. 2011. Patient self-report for evaluating mild cognitive impairment and prodromal Alzheimer's disease. *Alzheimers Res Ther*, 3, 35.
- FRANK, L., LLOYD, A., FLYNN, J. A., KLEINMAN, L., MATZA, L. S., MARGOLIS, M. K., BOWMAN, L. & BULLOCK, R. 2006b. Impact of cognitive impairment on mild dementia patients and mild cognitive impairment patients and their informants. *International Psychogeriatrics*, 18, 151-62.
- GALLAGHER, D., NI MHAOLAIN, A., CROSBY, L., RYAN, D., LACEY, L., COEN, R. F., WALSH, C., COAKLEY, D., WALSH, J. B., CUNNINGHAM, C. & LAWLOR, B. A. 2011. Dependence and caregiver burden in Alzheimer's disease and mild cognitive impairment. *Am J Alzheimers Dis Other Dement*, 26, 110-4.
- GANDEK, B., WARE, J. E., AARONSON, N. K., APOLONE, G., BJORNER, J. B., BRAZIER, J. E., BULLINGER, M., KAASA, S., LEPLEGE, A., PRIETO, L. & SULLIVAN, M.

1998. Cross-validation of item selection and scoring for the SF-12 Health Survey in nine countries: results from the IQOLA Project. International Quality of Life Assessment. *J Clin Epidemiol*, 51, 1171-8.
- GANGULI, M., SNITZ, B. E., SAXTON, J. A., CHANG, C. C., LEE, C. W., VANDER BILT, J., HUGHES, T. F., LOEWENSTEIN, D. A., UNVERZAGT, F. W. & PETERSEN, R. C. 2011. Outcomes of mild cognitive impairment by definition: a population study. *Arch Neurol*, 68, 761-7.
- GARAND, L., DEW, M. A., EAZOR, L. R., DEKOSKY, S. T. & REYNOLDS, C. F., 3RD 2005. Caregiving burden and psychiatric morbidity in spouses of persons with mild cognitive impairment. *Int J Geriatr Psychiatry*, 20, 512-22.
- GARAND, L., DEW, M. A., URDA, B., LINGLER, J. H., DEKOSKY, S. T. & REYNOLDS, C. F. 2007. Marital quality in the context of mild cognitive impairment. *West J Nurs Res*, 29, 976-92.
- GAUTHIER, S., REISBERG, B., ZAUDIG, M., PETERSEN, R. C., RITCHIE, K., BROICH, K., BELLEVILLE, S., BRODATY, H., BENNETT, D., CHERTKOW, H., CUMMINGS, J. L., DE LEON, M., FELDMAN, H., GANGULI, M., HAMPEL, H., SCHELTENS, P., TIERNEY, M. C., WHITEHOUSE, P. & WINBLAD, B. 2006. Mild cognitive impairment. *Lancet*, 367, 1262-70.
- GREEN, R. C., ROBERTS, J. S., CUPPLES, L. A., RELKIN, N. R., WHITEHOUSE, P. J., BROWN, T., ECKERT, S. L., BUTSON, M., SADOVNICK, A. D., QUAID, K. A., CHEN, C., COOK-DEEGAN, R. & FARRER, L. A. 2009. Disclosure of APOE genotype for risk of Alzheimer's disease. *N Engl J Med*, 361, 245-54.
- HAMANN, J., BRONNER, K., MARGULL, J., MENDEL, R., DIEHL-SCHMID, J., BUHNER, M., KLEIN, R., SCHNEIDER, A., KURZ, A. & PERNECZKY, R. 2011. Patient participation in medical and social decisions in Alzheimer's disease. *J Am Geriatr Soc*, 59, 2045-52.
- HENRY, J. D., VON HIPPEL, W., THOMPSON, C., PULFORD, P., SACHDEV, P. & BRODATY, H. 2012. Social behavior in mild cognitive impairment and early dementia. *J Clin Exp Neuropsychol*, 34, 806-13.
- HURT, C. S., BURNS, A., BROWN, R. G. & BARROWCLOUGH, C. 2012. Why don't older adults with subjective memory complaints seek help? *Int J Geriatr Psychiatry*, 27, 394-400.
- IMTIAZ, F., GASCOIGNE, G., LAI, L. M. & THOMSON, S. 2012. A survey of patient satisfaction with receiving a copy of their outpatient clinic letters. *European Journal of Surgical Oncology*, 38.
- ITO, Y. & URAKAMI, K. 2012. Evaluation of dementia-prevention classes for community-dwelling older adults with mild cognitive impairment. *Psychogeriatrics*, 12, 3-10.
- JENKINSON, C. 1999. Comparison of UK and US methods for weighting and scoring the SF-36 summary measures. *Journal of public health medicine*, 21, 372-6.
- JENKINSON, C., COULTER, A. & BRUSTER, S. 2002. The Picker Patient Experience Questionnaire: development and validation using data from in-patient surveys in five countries. *Int J Qual Health Care*, 14, 353-8.
- JENKINSON, C., FITZPATRICK, R., BRENNAN, C. & SWASH, M. 1999. Evidence for the validity and reliability of the ALS assessment questionnaire: the ALSAQ-40. *Amyotroph Lateral Scler Other Motor Neuron Disord*, 1, 33-40.
- JOHNS, E. K. 2008. The Montreal Cognitive Assessment (MOCA): Normative Data in the Community. *Canadian Journal of Geriatrics*, 11, 62.
- JONES, G., KENNEDY, S., BARNARD, A., WONG, J. & JENKINSON, C. 2001. Development of an endometriosis quality-of-life instrument: The Endometriosis Health Profile-30. *Obstet Gynecol*, 98, 258-64.
- JOOSTEN-WEYN BANNINGH, L., VERNOOIJ-DASSEN, M., RIKKERT, M. O. & TEUNISSE, J. P. 2008. Mild cognitive impairment: coping with an uncertain label. *International Journal Geriatric Psychiatry*, 23, 148-54.
- JOOSTEN-WEYN BANNINGH, L. W., PRINS, J. B., VERNOOIJ-DASSEN, M. J., WIJNEN, H. H., OLDE RIKKERT, M. G. & KESSELS, R. P. 2011. Group therapy for patients

- with mild cognitive impairment and their significant others: results of a waiting-list controlled trial. *Gerontology*, 57, 444-54.
- KERNICH, C. A. 2009. Patient and family fact sheet. Mild cognitive impairment. *Neurologist*, 15, 303-4.
- KESSELS, R. P. 2003. Patients' memory for medical information. *Journal of the Royal Society of Medicine*, 96, 219-22.
- KLINE, P. 1999. *Handbook of Psychological Testing*, Routledge.
- KUO, L. M. & SHYU, Y. I. 2010. Process of ambivalent normalisation: experience of family caregivers of elders with mild cognitive impairment in Taiwan. *J Clin Nurs*, 19, 3477-84.
- KUSLANSKY, G., KATZ, M., VERGHESE, J., HALL, C. B., LAPUERTA, P., LARUFFA, G. & LIPTON, R. B. 2004. Detecting dementia with the Hopkins Verbal Learning Test and the Mini-Mental State Examination. *Archives of Clinical Neuropsychology*, 19, 89-104.
- LAUTENSCHLAGER, N. T., COX, K. & KURZ, A. F. 2010. Physical activity and mild cognitive impairment and Alzheimer's disease. *Curr Neurol Neurosci Rep*, 10, 352-8.
- LEE, C. E., BROWELL, L. M. & JONES, D. L. 2008a. Measuring health in patients with cervical and lumbosacral spinal disorders: is the 12-item short-form health survey a valid alternative for the 36-item short-form health survey? *Arch Phys Med Rehabil*, 89, 829-33.
- LEE, K. S., KIM, E. A., HONG, C. H., LEE, D. W., OH, B. H. & CHEONG, H. K. 2008b. Clock drawing test in mild cognitive impairment: quantitative analysis of four scoring methods and qualitative analysis. *Dementia and Geriatric Cognitive Disorders*, 26, 483-9.
- LEIDY, N. K., REVICKI, D. A. & GENESTE, B. 1999. Recommendations for evaluating the validity of quality of life claims for labeling and promotion. *Value Health*, 2, 113-27.
- LIKERT, R. 1932. A technique for the measurements of attitudes. *Archives of Psychology*, 22, 1-55.
- LIN, F. & HEIDRICH, S. M. 2012. Role of older adult's illness schemata in coping with mild cognitive impairment. *J Psychosom Res*, 72, 357-63.
- LINGLER, J. H., NIGHTINGALE, M. C., ERLIN, J. A., KANE, A. L., REYNOLDS, C. F., 3RD, SCHULZ, R. & DEKOSKY, S. T. 2006. Making sense of mild cognitive impairment: a qualitative exploration of the patient's experience. *Gerontologist*, 46, 791-800.
- LOGSDON, R. G., GIBBONS, L. E., MCCURRY, S. M. & TERI, L. 2002. Assessing quality of life in older adults with cognitive impairment. *Psychosom Med*, 64, 510-9.
- LU, Y.-F. Y., HAASE, J. E. & FARRAN, C. J. 2007a. Perspectives of Persons With Mild Cognitive Impairment: Sense of Being Able. *Alzheimer's Care Today*, 8, 75-86.
- LU, Y. F., AUSTROM, M. G., PERKINS, S. M., BAKAS, T., FARLOW, M. R., HE, F., JIN, S. & GAMST, A. 2007b. Depressed mood in informal caregivers of individuals with mild cognitive impairment. *American Journal of Alzheimer's Disease and Other Dementias*, 22, 273-85.
- LU, Y. F. & HAASE, J. E. 2009. Experience and perspectives of caregivers of spouse with mild cognitive impairment. *Current Alzheimer Research*, 6, 384-91.
- LU, Y. Y. & HAASE, J. E. 2011. Content validity and acceptability of the daily enhancement of meaningful activity program: intervention for mild cognitive impairment patient-spouse dyads. *J Neurosci Nurs*, 43, 317-28.
- LUCK, T., LUPPA, M., BRIEL, S. & RIEDEL-HELLER, S. G. 2010a. Incidence of mild cognitive impairment: A systematic review. *Dementia and Geriatric Cognitive Disorders*, 29 (2), 164-175.
- LUCK, T., RIEDEL-HELLER, S. G., LUPPA, M., WIESE, B., WOLLNY, A., WAGNER, M., BICKEL, H., WEYERER, S., PENTZEK, M., HALLER, F., MOESCH, E., WERLE, J., EISELE, M., MAIER, W., VAN DEN BUSSCHE, H. & KADUSZKIEWICZ, H. 2010b. Risk factors for incident mild cognitive impairment--results from the German Study on

- Ageing, Cognition and Dementia in Primary Care Patients (AgeCoDe). *Acta Psychiatr Scand*, 121, 260-72.
- LYKETSOS, C. G., LOPEZ, O., JONES, B., FITZPATRICK, A. L., BREITNER, J. & DEKOSKY, S. 2002. Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: results from the cardiovascular health study. *Journal of the American Medical Association*, 288, 1475-83.
- MACFARLANE, H., KINIRONS, M. T. & BULTITUDE, M. F. 2012. WWW. Do not forget older people. *Age and ageing*, 41, 807-10.
- MARTIN, M., CLARE, L., ALTGASSEN, A. M., CAMERON, M. H. & ZEHNDER, F. 2011. Cognition-based interventions for healthy older people and people with mild cognitive impairment. *Cochrane Database Syst Rev*, CD006220.
- MARTINEZ, F. J., RACZEK, A. E., SEIFER, F. D., CONOSCENTI, C. S., CURTICE, T. G., D'ELETTO, T., COTE, C., HAWKINS, C. & PHILLIPS, A. L. 2008. Development and initial validation of a self-scored COPD Population Screener Questionnaire (COPD-PS). *COPD*, 5, 85-95.
- MATTHEWS, F. E., STEPHAN, B. C., MCKEITH, I. G., BOND, J. & BRAYNE, C. 2008. Two-year progression from mild cognitive impairment to dementia: to what extent do different definitions agree? *J Am Geriatr Soc*, 56, 1424-33.
- MCDOWELL, I., KRISTJANSSON, B., HILL, G. B. & HÉBERT, R. 1997. Community screening for dementia: The Mini Mental State Exam (MMSE) and modified Mini-Mental State Exam (3MS) compared. *Journal of Clinical Epidemiology*, 50, 377-383.
- MCILVANE, J. M., POPA, M. A., ROBINSON, B., HOUSEWEART, K. & HALEY, W. E. 2008. Perceptions of illness, coping, and well-being in persons with mild cognitive impairment and their care partners. *Alzheimer Disease and Associated Disorders*, 22, 284-92.
- MENON, R. & LARNER, A. J. 2011. Use of cognitive screening instruments in primary care: The impact of national dementia directives (NICE/SCIE, National Dementia Strategy). *Family Practice*, 28, 272-276.
- MITCHELL, A. J. 2009. A meta-analysis of the accuracy of the mini-mental state examination in the detection of dementia and mild cognitive impairment. *Journal of Psychiatric Research*, 43, 411-31.
- MITCHELL, A. J., MEADER, N. & PENTZEK, M. 2011. Clinical recognition of dementia and cognitive impairment in primary care: a meta-analysis of physician accuracy. *Acta Psychiatr Scand*.
- MITCHELL, A. J. & SHIRI-FESHKI, M. 2009. Rate of progression of mild cognitive impairment to dementia--meta-analysis of 41 robust inception cohort studies. *Acta Psychiatrica Scandinavica*, 119, 252-65.
- MONIZ-COOK, E., VERNOOIJ-DASSEN, M., WOODS, R., VERHEY, F., CHATTAT, R., DE, M., MOUNTAIN, G., O'CONNELL, M., HARRISON, J., VASSE, E., DROES, R. M., ORRELL, M. & INTERDEM, I. N. T. E. R. D. E. M. 2008. A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging & Mental Health*, 12, 14-29.
- MORGAN, G. H., GARAND, L. I. & LINGLER, J. H. 2012. Self-initiated health behaviors following a diagnosis of mild cognitive impairment. *Res Gerontol Nurs*, 5, 94-100.
- MORRIS, J. C. 1993. The Clinical Dementia Rating (CDR): current version and scoring rules. *Neurology*, 43, 2412-4.
- NASREDDINE, Z. S., PHILLIPS, N. A., BEDIRIAN, V., CHARBONNEAU, S., WHITEHEAD, V., COLLIN, I., CUMMINGS, J. L. & CHERTKOW, H. 2005. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc*, 53, 695-9.
- NATIONAL INSTITUTE FOR CLINICAL EXCELLENCE AND SOCIAL CARE INSTITUTE FOR EXCELLENCE (ENGLAND AND WALES) 2006. Dementia: Supporting people with dementia and their carers in health and social care.

- NOVELLA, J. L., JOCHUM, C., ANKRI, J., MORRONE, I., JOLLY, D. & BLANCHARD, F. 2001. Measuring general health status in dementia: practical and methodological issues in using the SF-36. *Aging*, 13, 362-9.
- NUNNALLY, J. & BERNSTEIN, I. 1994. *Psychometric theory*, New York, McGraw Hill.
- OFFICE OF NATIONAL STATISTICS 2002. Social Focus in Brief: Ethnicity 2012. London: National Statistics.
- PALMER, K., BACKMAN, L., WINBLAD, B. & FRATIGLIONI, L. 2008. Mild cognitive impairment in the general population: occurrence and progression to Alzheimer disease. *American Journal of Geriatric Psychiatry*, 16, 603-11.
- PALMER, K., MUSICCO, M. & CALTAGIRONE, C. 2010. Are guidelines needed for the diagnosis and management of incipient Alzheimer's disease and mild cognitive impairment? *Int J Alzheimers Dis*, 2010, 417615.
- PETERSEN, R. C., DOODY, R., KURZ, A., MOHS, R. C., MORRIS, J. C., RABINS, P. V., RITCHIE, K., ROSSOR, M., THAL, L. & WINBLAD, B. 2001a. Current concepts in mild cognitive impairment. *Arch Neurol*, 58, 1985-92.
- PETERSEN, R. C., ROBERTS, R. O., KNOPMAN, D. S., BOEVE, B. F., GEDA, Y. E., IVNIK, R. J., SMITH, G. E. & JACK, C. R., JR. 2009. Mild cognitive impairment: ten years later. *Arch Neurol*, 66, 1447-55.
- PETERSEN, R. C., SMITH, G. E., WARING, S. C., IVNIK, R. J., TANGALOS, E. G. & KOKMEN, E. 1999. Mild cognitive impairment: Clinical characterization and outcome. *Archives of Neurology*, 56 (3), 303-308.
- PETERSEN, R. C., STEVENS, J. C., GANGULI, M., TANGALOS, E. G., CUMMINGS, J. L. & DEKOSKY, S. T. 2001b. Practice parameter: early detection of dementia: mild cognitive impairment (an evidence-based review). Report of the Quality Standards Subcommittee of the American Academy of Neurology. *Neurology*, 56, 1133-42.
- PINQUART, M. & SORENSEN, S. 2006. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*, 18, 577-95.
- PIRES, C., SILVA, D., MAROCO, J., GINO, S., MENDES, T., SCHMAND, B. A., GUERREIRO, M. & DE MENDONCA, A. 2012. Memory complaints associated with seeking clinical care. *Int J Alzheimers Dis*, 2012, 725329.
- READY, R. E., OTT, B. R. & GRACE, J. 2006. Insight and cognitive impairment: effects on quality-of-life reports from mild cognitive impairment and Alzheimer's disease patients. *Am J Alzheimers Dis Other Dement*, 21, 242-8.
- REVICKI, D. A. 2002. Consistent patient-reported outcomes. *Value Health*, 5, 295-6.
- RITCHIE, K. 2004. Mild cognitive impairment: an epidemiological perspective. *Dialogues Clin Neurosci*, 6, 401-8.
- ROBERTO, K. A., BLIESZNER, R., MCCANN, B. R. & MCPHERSON, M. C. 2011. Family Triad Perceptions of Mild Cognitive Impairment. *J Gerontol B Psychol Sci Soc Sci*, 66, 758-68.
- ROBERTS, J. L. & CLARE, L. 2012. Meta-representational awareness in mild cognitive impairment: An interpretative phenomenological analysis. *Aging & Mental Health*, 17, 300-09.
- ROBERTS, J. L., CLARE, L. & WOODS, R. T. 2009. Subjective memory complaints and awareness of memory functioning in mild cognitive impairment: a systematic review. *Dement Geriatr Cogn Disord*, 28, 95-109.
- ROBERTS, J. S., KARLAWISH, J. H., UHLMANN, W. R., PETERSEN, R. C. & GREEN, R. C. 2010. Mild cognitive impairment in clinical care: a survey of American Academy of Neurology members. *Neurology*, 75, 425-31.
- ROCKWOOD, K., GAUTHIER, S. & EDS 2006. *Trial Designs and Outcomes in Dementia Therapeutic Research*, London and New York, Taylor and Francis Group.
- RODDA, J., GANDHI, S. D., MUKADAM, N. & WALKER, Z. 2012. Attitudes of UK psychiatrists to the diagnosis of MCI in clinical practice. *Int Psychogeriatr*, 25, 286-91.

- ROYALL, D. R., CORDES, J. A. & POLK, M. 1998. CLOX: an executive clock drawing task. *Journal of neurology, neurosurgery, and psychiatry*, 64, 588-94.
- RYAN, K. A., WELDON, A., HUBY, N. M., PERSAD, C., BHAUMIK, A. K., HEIDEBRINK, J. L., BARBAS, N., STAFFEND, N., FRANTI, L. & GIORDANI, B. 2010. Caregiver support service needs for patients with mild cognitive impairment and Alzheimer disease. *Alzheimer Disease and Associated Disorders*, 24, 171-6.
- SALYERS, M. P., BOSWORTH, H. B., SWANSON, J. W., LAMB-PAGONE, J. & OSHER, F. C. 2000. Reliability and validity of the SF-12 health survey among people with severe mental illness. *Med Care*, 38, 1141-50.
- SAVLA, J., ROBERTO, K. A., BLIESZNER, R., COX, M. & GWAZDAUSKAS, F. 2011. Effects of Daily Stressors on the Psychological and Biological Well-being of Spouses of Persons With Mild Cognitive Impairment. *J Gerontol B Psychol Sci Soc Sci*, 66B, 653-664.
- SCHMID, R., ESCHEN, A., RUEGGER-FREY, B. & MARTIN, M. 2012. Instruments for comprehensive needs assessment in individuals with cognitive complaints, mild cognitive impairment or dementia: a systematic review. *Int J Geriatr Psychiatry*, 27, 329-41.
- SIMON, S. S., YOKOMIZO, J. E. & BOTTINO, C. M. 2012. Cognitive intervention in amnesic Mild Cognitive Impairment: a systematic review. *Neurosci Biobehav Rev*, 36, 1163-78.
- SMITH, A. D., SMITH, S. M., DE JAGER, C. A., WHITBREAD, P., JOHNSTON, C., AGACINSKI, G., OULHAJ, A., BRADLEY, K. M., JACOBY, R. & REFSUM, H. 2010. Homocysteine-lowering by B vitamins slows the rate of accelerated brain atrophy in mild cognitive impairment: a randomized controlled trial. *Public Library of Science* 5, e12244.
- STARKSTEIN, S. E., CHEMERINSKI, E., SABE, L., KUZIS, G., PETRACCA, G., TESON, A. & LEIGUARDA, R. 1997. Prospective longitudinal study of depression and anosognosia in Alzheimer's disease. *Br J Psychiatry*, 171, 47-52.
- STREINER, D. L. & NORMAN, G. R. 2003. *Health Measurement Scales: a practical guide to their development and use*, Oxford University Press.
- TABERT, M. H., ALBERT, S. M., BORUKHOVA-MILOV, L., CAMACHO, Y., PELTON, G., LIU, X., STERN, Y. & DEVANAND, D. P. 2002. Functional deficits in patients with mild cognitive impairment: prediction of AD. *Neurology*, 58, 758-64.
- TAHIR, T. A., BISSON, J. I. & WILCOX, J. 2005. Copying clinic letters to psychiatric patients. *Psychiatric Bulletin*, 29, 327-329.
- TATSUMI, H., YAMAMOTO, M., NAKAAKI, S., HADANO, K. & NARUMOTO, J. 2011. Utility of the Quality of Life-Alzheimer's Disease Scale for mild cognitive impairment. *Psychiatry Clin Neurosci*, 65, 533.
- THE NHS INFORMATION CENTRE, S. C. T. 2010. Survey of Carers in Households 2009/10.
- THOMAS, P., LALLOUE, F., PREUX, P. M., HAZIF-THOMAS, C., PARIEL, S., INSCALE, R., BELMIN, J. & CLEMENT, J. P. 2006. Dementia patients caregivers quality of life: the PIXEL study. *Int J Geriatr Psychiatry*, 21, 50-6.
- TORPY, J. M., LYNM, C. & GLASS, R. M. 2008. JAMA patient page. Mild cognitive impairment. *JAMA*, 300, 1610.
- US DEPARTMENT OF HEALTH AND HUMAN SERVICES, FOOD AND DRUG ADMINISTRATION, CENTER FOR DRUG EVALUATION AND RESEARCH & CENTER FOR DEVICES AND RADIOLOGICAL HEALTH 2009. Guidance for Industry. Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labelling Claims.
- VAN HOUT, H. P. J., VERNOOIJ-DASSEN, M. J. F. J., HOEFNAGELS, W. H. L. & GROL, R. P. T. M. 2001. Measuring the opinions of memory clinic users: patients, relatives and general practitioners. *International Journal of Geriatric Psychiatry*, 16, 846-851.
- VOGEL, A., STOKHOLM, J., GADE, A., ANDERSEN, B. B., HEJL, A. M. & WALDEMAR, G. 2004. Awareness of deficits in mild cognitive impairment and Alzheimer's disease: do

- MCI patients have impaired insight? *Dementia and Geriatric Cognitive Disorders*, 17, 181-7.
- WACKERBARTH, S. B., STREAMS, M. E. & SMITH, M. K. 2002. Capturing the insights of family caregivers: survey item generation with a coupled interview/focus group process. *Qual Health Res*, 12, 1141-54.
- WAHLUND, L. O., PIHLSTRAND, E. & JONHAGEN, M. E. 2003. Mild cognitive impairment: experience from a memory clinic. *Acta Neurol Scand Suppl*, 179, 21-4.
- WALDORFF, F. B., RISHOJ, S. & WALDEMAR, G. 2008. If you don't ask (about memory), they probably won't tell. *J Fam Pract*, 57, 41-4.
- WARE, J., KOSINSKI, M. & KELLER, S. 1996. A 12-item short-form health survey: Construction of Scales and preliminary tests of reliability and validity. *Medical Care*, 34, 220-233.
- WARE, J., KOSINSKI, M., TURNER-BOWKER, D. & GANDEK, B. 2007. *User's Manual for the SF-12v2 Health Survey*, QualityMetric Incorporated and Health Assessment Lab.
- WARE, J. E., JR. & SHERBOURNE, C. D. 1992. The MOS 36-item short-form health survey (SF-36). I. Conceptual framework and item selection. *Med Care*, 30, 473-83.
- WARE, J. E., KOSINSKI, M., GANDEK, B., SUNDRAM, M., BJORNER, J. B., TURNER-BOWKER, D. M. & MARUISH, M. E. 2010. *User's Manual For The SF-12v2 Health Survey* Lincoln.
- WEINER, M. W., VEITCH, D. P., AISEN, P. S., BECKETT, L. A., CAIRNS, N. J., GREEN, R. C., HARVEY, D., JACK, C. R., JAGUST, W., LIU, E., MORRIS, J. C., PETERSEN, R. C., SAYKIN, A. J., SCHMIDT, M. E., SHAW, L., SIUCIAK, J. A., SOARES, H., TOGA, A. W. & TROJANOWSKI, J. Q. 2012. The Alzheimer's Disease Neuroimaging Initiative: a review of papers published since its inception. *Alzheimers Dement*, 8, S1-68.
- WERNER, P. 2012. Mild Cognitive Impairment and Caregiver Burden: A Critical Review and Research Agenda. *Public Health Reviews*, 34.
- WESTON, A., BARTON, C., LESSELYONG, J. & YAFFE, K. 2011. Functional deficits among patients with mild cognitive impairment. *Alzheimers Dement*, 7, 611-4.
- WILLIAMS, S. K. & KELSEY, C. R. 2009. Copying clinic letters to patients: A patient survey. *Rheumatology*, 48, i110-i111.
- WINBLAD, B., BRODATY, H., GAUTHIER, S., MORRIS, J. C., ORGOGOZO, J. M., ROCKWOOD, K., SCHNEIDER, L., TAKEDA, M., TARIOT, P. & WILKINSON, D. 2001. Pharmacotherapy of Alzheimer's disease: is there a need to redefine treatment success? *Int J Geriatr Psychiatry*, 16, 653-66.
- WINBLAD, B., PALMER, K., KIVIPALTO, M., JELIC, V., FRATIGLIONI, L., WAHLUND, L. O., NORDBERG, A., BACKMAN, L., ALBERT, M., ALMKVIST, O., ARAI, H., BASUN, H., BLENNOW, K., DE LEON, M., DECARLI, C., ERKINJUNTTI, T., GIACOBINI, E., GRAFF, C., HARDY, J., JACK, C., JORM, A., RITCHIE, K., VAN DUIJN, C., VISSER, P. & PETERSEN, R. C. 2004. Mild cognitive impairment--beyond controversies, towards a consensus: report of the International Working Group on Mild Cognitive Impairment. *J Intern Med*, 256, 240-6.
- WORLD HEALTH ORGANISATION 1992. The ICD-10 classification of mental and behavioural disorders : clinical descriptions and diagnostic guidelines.
- WRIGHT, J. 2009. Mild cognitive impairment (version 17.2). *UpToDate* [Online].
- ZIGMOND, A. S. & SNAITH, R. P. 1983. The hospital anxiety and depression scale. *Acta Psychiatr Scand*, 67, 361-70.

Appendices

Appendix 1 – Interview Topic Guides

Interview Topic Guide for People With Mild Cognitive Impairment

- Tell me a bit about your background.....
- Looking back what do you think the first signs were that there was a problem?
- Tell me about daily life with your memory problem
- Reasons for initial presentation to primary care
- Experience of consultation with primary care physician
- Experience of consultation in memory service including
 - understanding of reasons for referral
 - process of assessment including cognitive testing
 - receiving the diagnosis of mild cognitive impairment (MCI)
 - understanding of the diagnosis (the meaning and implications of the diagnosis of MCI)
 - information provided by healthcare professionals at each stage
- Other sources of information accessed
- Practical strategies adopted to aid memory
- Impact of the problems described on relationship with spouse / family members / social contacts
- Perceptions about the future
- How the process of consultation, diagnosis and support might be different
- Day to day issues caused by memory problems
- Do you think you have more or less problems than others of your age
- Influence of their experiences of other people with memory problems on their perceptions of their own problem

- Is there anything else I haven't covered?

Interview Topic Guide for Advocates

- Tell me a bit about your background....
- Looking back what were the first signs that something might be amiss?
- Tell me about daily life with the person with MCI (PWMCI)
- Experience of consultation with general practitioner (GP) (if advocate was present) – their role
- Experience of consultation in memory service including (if advocate was present) – their role
- Information given by primary care / Memory service specific to their needs as an advocate
- Other sources of information accessed
- Communication with the PWMCI about their memory problems
- Impact on their relationship with the PWMCI / other family members / friends
- Impact / burden on them, coping strategies
- Experience of other people with memory problems and how this influences their perceptions of the patients problems
- Perceptions about the future
- How the process of consultation, diagnosis and support might be different
- Anything I haven't covered?

Appendix 2 – Examples of Study Literature from Interview Stage

Initial Information Sheet – Person With Mild Cognitive Impairment - Interview



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940

Fax: 01865 231525

katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology

John Radcliffe Hospital

Headington

Oxford

OX3 9DU

Oxford Radcliffe Hospitals NHS Trust

Research into Issues Surrounding the Diagnosis of Mild Cognitive Impairment: Patient Information Sheet

Research Ethics Committee: Southampton and South West Hampshire Research Ethics Committee B

Study reference number from above REC: 10/H0504/62

Principal Researcher: Dr Katherine Dean

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the study is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you may have.

What is the purpose of the study?

The purpose of this study is to look at the issues surrounding the diagnosis 'Mild Cognitive Impairment (MCI)' – that is memory problems that are not severe enough to be called 'dementia'. Our present information about what the common problems are and how best to support people with this condition is limited. This information sheet tells you how you can help us increase our understanding and so improve current practice and support.

This study aims to identify the problems that people recently diagnosed with MCI and their family members or close friends have faced. From this information the aim is to develop a 'support programme', for future use in Memory Clinics and, to provide better information and support to people diagnosed with MCI and those close to them.

Why have I been invited?

You have been invited because you have had a memory assessment in the Memory Clinic or at home and have diagnosed with MCI.

Do I have to take part?

No. It is up to you to decide whether to join the study. We will describe the study and go through this information sheet. If you agree to take part you will be asked to sign a consent form. You are free to withdraw at any time without giving a reason. This would not affect the standard of care you receive. All information about you will be treated in strict confidence.

1
Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC reference 10/H0504/62
Patient Laminar Interview ORH/Version 3/28/01/11



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

What will happen to me if I take part?

1. We will record your contact details and pass them on to a member of the research team.
2. We will ask you to sign a form to confirm that you agree to being contacted about taking part in this study and that you agree to the research team viewing your medical notes. Part of this study involves talking to the relatives and friends of people with MCI to find out how they have been affected. If you do agree to take part in the study, at a later date we will ask you if there is a close family member or friend who you would be happy for us to talk to and who you think might be interested in taking part in the study. If you think you might nominate someone later we will ask you to indicate on the form that you would be happy for us to talk to the person whose details you give us.
3. Our team will look at your medical notes to make sure this study is appropriate for you.
4. We will send you some more detailed information about the study by post in the next week or two. We will also send you some information to be passed on to a friend or relative who you would be happy for us to talk to about your memory problems and whom you think might also be interested in taking part in the study.
5. We will contact you by telephone once you have had some time to read this information. If you are still interested in taking part in the study we will arrange to meet you at a time and location convenient to you: this could either be at your home, the home of a friend or relative or in the hospital outpatient department.
6. At the meeting we will interview you about the difficulties that your memory problems have caused you. The meeting is likely to take 1 – 2 hours in total.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be strictly confidential.

2

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC reference 10/H0504/62
Patient Laminar Interview ORH/Version 3/28/01/11



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

Further Information and Contact Details

General information about research

INVOLVE

Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD.

Website: <http://www.invo.org.uk/>

Tel: 02380 651088

Fax: 02380 652885

Email: admin@invo.org.uk

INVOLVE is a national advisory group, funded through the NHS National Institute for Health Research. Its role is to support and promote active public involvement in NHS, public health and social care research. INVOLVE can provide information about research and answer any questions you may have.

For specific information about this project

Dr Kate Dean (researcher)

Nuffield Department of Medicine
John Radcliffe Hospital
Headley Way
Oxford
OX3 9DU
Telephone: 01865 234940
Email: katherine.dean@ndm.ox.ac.uk

For advice about whether to participate:

Dr Kate Dean (researcher) – as above

3

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC reference 10/H0504/62
Patient Laminar Interview ORH/Version 3/28/01/11



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals **NHS**
NHS Trust

Oxford Radcliffe Hospitals NHS Trust Patient Advice and Liaison Service (PALS)

John Radcliffe Hospital
Headley Way
Oxford
OX3 9DU

Telephone: 01865 221473

Email: PALSJR@orh.nhs.uk

The PALS offers support, information and assistance to patients, relatives and visitors. The PALS staff are available to assist with any queries or concerns you may have about the services offered by the Oxford Radcliffe hospitals.

University of Oxford Clinical Trials and Research Governance Office

Manor House
John Radcliffe Hospital
Headington
Oxford
OX3 9DZ

Telephone: 01865 222757

We will give you a copy of this information leaflet to keep.

4

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC reference 10/H0504/62
Patient Laminar Interview ORH/Version 3/28/01/11

Full Information Sheet – Person With Mild Cognitive Impairment - Interview



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals NHS Trust

Research into Issues Surrounding the Diagnosis of Mild Cognitive Impairment: Patient Information Sheet

Research Ethics Committee: Southampton and South West Hampshire Research Ethics Committee B
Study reference number from above REC: 10/H0504/62
Principal Researcher: Dr Katherine Dean

Thank you for agreeing to consider taking part in our research study. Before you decide we would like you to understand why the study is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you may have. This should take about ten minutes. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

Part 1 tells you about the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study

Part 1

What is the purpose of the study?

The purpose of this study is to look at the issues surrounding the diagnosis of 'Mild Cognitive Impairment (MCI)' – that is memory problems that are not severe enough to be called 'dementia'. Our present information about what the common problems are and how best to support people with this condition is limited. This information sheet tells you how you can help us increase our understanding and so improve current practice and support.

This study aims to identify the problems that people recently diagnosed with MCI and their family members or close friends have faced. From this information the aim is to develop a 'support programme' for future use in Memory Clinics and to provide better information and support to people diagnosed with MCI and those close to them.

We will be inviting about 50 people to take part in this stage of the study.

Why have I been invited?

You have been invited because you have recently been assessed in a Memory Clinic and diagnosed with MCI by Prof Wilcock, Dr Stewart or one of

1
Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

their team or had a memory assessment at home. You agreed to your details being passed on to the research team to discuss whether you would like to be involved in this study.

Do I have to take part?

No. It is up to you to decide whether to take part in the study. We will describe the study and go through this information sheet. If you agree to take part you will be asked to sign a consent form. You are free to withdraw at any time without giving a reason. This would not affect the standard of care you receive. All information about you will be treated in strict confidence.

What will happen to me if I take part?

- We will telephone you within the next two weeks to arrange to meet with you at a time and place that is convenient to you. This could either be at your home, the home of a friend or relative or in the hospital outpatient department. The meeting is likely to take 1 – 2 hours in total.
- Part of this study involves finding out about the issues that affect close family members and friends of people with MCI. If you have a friend or relative who you think has been affected by your memory problems, who you would be happy for us to talk to about these problems and who you think might be interested in taking part in this study we would like to talk to them too. If you indicated on the form that you completed in clinic that you would be happy for the research team to talk to a friend or relative of yours you should have received, in addition to this information sheet, a second 'information pack' which we would like you to pass on to a suitable friend or relative if you have one. Please note that by passing the pack to this friend or relative you would be indicating that you are happy for the research team to discuss your memory problems with that person. The pack gives detailed information about the study (similar to that given here) and includes a reply slip which your friend or relative can return to us if they are interested in taking part in the study. If your friend or relative agrees to take part we will organise a meeting to interview them. Unless you both want to be interviewed together we would talk to you separately to make sure that what you discuss with the researcher remains confidential. Even if you do not have a family member or close friend that you agree to us to talk to we would still like to interview you.

2

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

- Before starting the interview we will check that you understand what taking part in this study involves and ask you to sign a form to say you are happy to do so.
- It is important to know whether people taking part in this study might be depressed. Therefore, before we begin, we will go through a short questionnaire to check for symptoms of depression. If the results of this suggest you may have symptoms of depression with your permission we will write to your GP to tell them about the results of the questionnaire and ask them to see you to discuss this further. As long as you were happy to proceed we would still go ahead with the interview.
- It is important that all people with MCI taking part in this study have had their memory problems measured in the same way. Therefore, before proceeding with the interview, we may go through a short set of questions with you to assess your memory problems.
- The main part of the study involves a discussion with the researcher about the concerns and difficulties you have experienced as a result of your memory problems and in the process of having them assessed. The researcher will guide the discussion around list of topics but you will be free to add anything that is important to you. The type of subjects that will be covered will include:
 - Your experiences of being assessed at the GP surgery and at the Memory Clinic / at home (both positive and negative)
 - How these experiences could have been different
 - What information you have been given about your condition
 - What your concerns are for the future

The discussion should take 1 – 2 hours in total but may be longer or shorter depending on how much you have to say. It will be audio-recorded so that it can be analysed afterwards. The audio-recording will be stored securely and the transcript from it will be anonymised. We may use some direct quotations of things you have said in the interview when we publish our results but we will take care not to use anything that you could be identified from.

3

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

Expenses

If you choose to travel to the hospital outpatient clinic or house of a relative or friend to take part in the study we will reimburse reasonable travel expenses. Light refreshments will be provided at the outpatient clinic at no cost to you

What will I have to do?

If you choose to take part in the study:

- When the researcher telephones you you would need to agree a convenient time and place to meet them, setting aside 1 - 2 hours for this
- If you would be happy for the research team to talk to a friend or relative about your memory problems you would need to pass the enclosed information pack on to them.
- You would need to sign a 'consent form' to say that you understand what taking part in the study involves and that you are happy to do so.
- With the researcher you would complete a short verbal questionnaire to check for symptoms of depression.
- In some cases the researcher may need to complete a second short set of questions with you to assess your memory.
- You would discuss a range of topics focussing on your memory difficulties and the process of assessment with the researcher for 1 – 2 hours. This discussion would be audio-recorded.

What are the possible disadvantages of taking part?

You may find it time consuming and inconvenient to arrange and take part in the meeting with the researcher. We will try to minimise the inconvenience by arranging the meeting at a time and location that is convenient to you. We will reimburse reasonable travel expenses if you choose to travel to the hospital or someone else's house for the meeting.

As part of the study we will check for symptoms of depression. There is a chance that the test we carry out could suggest that you have symptoms of depression. If this does happen, with your permission, we will write to your GP to tell them about the result and ask them to see you to discuss this further.

4

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

You may find discussing some of the issues surrounding your memory problems distressing. The researcher will be sensitive to this and the discussion can be stopped at any time if you feel uncomfortable.

What are the possible benefits of taking part?

You may find it helpful to discuss some of the issues surrounding your memory problems that have been worrying you. We cannot promise that the results of the study will help you directly but the information we get from this study will help improve the support we can provide for people with MCI and their close family members and friends in the future.

What if there is a problem?

Any complaint you have about the way you have been dealt with in the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

What happens now?

If you have found the information in Part 1 interesting and you are considering taking part in the study, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, including during the interview if you wish. You do not have to give a reason and this will not affect your care. Any information collected may still be used but it would not be possible to identify you from this information.

What if there is a problem?

- **Complaints:** If you have a concern about any aspect of this study you should ask to speak to the lead researcher, Dr Kate Dean, who will do her best to answer your questions. She can be contacted on 01865 234940. If you remain unhappy and wish to complain formally about any aspect of the way in which you have been

5

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

approached or treated during the course of this study you can do this via the University of Oxford Clinical Trials and Research Governance office on 01865 222757.

- **Harm:** Given the nature of this study, it is highly unlikely that you will suffer harm by taking part, however if you are harmed by participation in the study, you may have grounds for legal action for compensation against the University of Oxford.

Will my taking part in this trial be kept confidential?

Yes. All information which is collected about you will be kept strictly confidential at all stages of the study. This includes:

- If you agree to being contacted about taking part in the study your name and contact details will be recorded and passed on to the research team, they will store these securely.
- The questionnaire to detect symptoms of depression, the short assessment of your memory problems and the interview will be carried out by the researcher in a location where privacy can be assured. If a family member / close friend has also agreed to take part in the study they will be interviewed separately (unless you both request that you are interviewed together) to protect your privacy.
- Although the interview will be audio-recorded it will be anonymous – you will be given a code to identify you and only the researcher will know this code. It will not be possible for anyone else to tell who gave the answers on the tape once it is recorded. The audio-recording will be stored and transported securely.
- The recording of the interview will be typed out - the person who does this will not know the identity of the person being interviewed in the recording and will be bound by confidentiality regulations.
- The results of many interviews will be analysed together to identify issues that are common in people with MCI. The information will be used to produce a questionnaire which will be sent to a large number of people with MCI and their relatives and friends. The results of the questionnaire will be used to produce guidance for Memory Clinics about the best way to support people with MCI and their families and

6

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals NHS Trust

close friends. The results will be published in a journal and possibly the internet and may be sent out to Memory Clinics across the country. You will not be identified in the published results. When the results are published direct quotations of things that have been said in interviews may be used but once again these will be anonymous and we will not publish any quotations where it would be possible for someone to identify you from what has been said.

- If you join the study some parts of your medical records and the data collected may be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant. These people may include the sponsor of this study (ie. The University of Oxford), regulatory authorities and research ethics committees including the Research and Development departments at The University of Oxford and the Oxford Radcliffe Hospitals NHS Trust.
- Identifiable data about you will not be retained any longer than necessary and will be destroyed by the end of the study (August 2012). Non-identifiable data from the study will be retained for 5 years as per University of Oxford regulations. Paper recorded data will be shredded and electronic records wiped by the University's Information Management Service.

Will my General Practitioner be involved?

We will not write to your GP unless you give us permission to do so however there are two circumstances when we may ask for your permission to write to them:

- If the questionnaire suggests that you may have symptoms of depression in which case, if you agree, we will write to your GP to tell them about this result and ask them to see you to talk about how best to help you.
- If an issue is identified during the interview that you or the researcher thinks your GP may be able to help with we will, with your permission, write to your GP about this.

7

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

What will happen to the information you collect about me?

Information collected about you, both written and audio-recorded, will be securely stored on NHS or University of Oxford premises. Certain authorised people, who have a duty of confidentiality to you as a research participant, may have access to the information.

At the end of the study information will be stored for 5 years in anonymised form and then destroyed. Paper records will be shredded and electronic data wiped by the University's Information Management Service.

If your memory problems worsen during the study to the extent that you are no longer able to understand the risks and benefits of taking part no further information will be collected about you. Any study information already collected about you may still be used in anonymised form.

What will happen to the results of the research study?

The answers you give in your interview will be analysed along with answers from the other people taking part in the study. In this way common issues faced by people with MCI and their relatives / close friends will be identified. Using these results a questionnaire about the experiences of people with MCI will be developed and sent out to a large number of people with MCI. Using the results of the questionnaire a document suggesting the best way to support this group of people will be produced. The results and the support document will be published in print and possibly on the internet. You will not be identified in any publication. We will send you a summary of the results of the study once it is completed.

Who is organising and funding the research study?

The University of Oxford is organising the study and BUPA Giving is providing funding. The doctor conducting the study is being paid by the University of Oxford, funded by the grant from BUPA Giving, to do so.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed, and given a favourable opinion, by Southampton and South West Hampshire Research Ethics Committee B.

8

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

Further Information and Contact Details

General information about research:

INVOLVE

Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD.

Website: <http://www.invo.org.uk/>

Tel: 02380 651088

Fax: 02380 652885

Email: admin@invo.org.uk

INVOLVE is national advisory group, funded through the NHS National Institute for Health Research whose role is to support and promote active public involvement in NHS, public health and social care research. INVOLVE can provide information about research and answer any questions you may have.

UK Clinical Research Collaboration

Understanding Clinical Trials Booklet: may be downloaded at:
<http://www.ukcrc.org/index.aspx?o=1475>

Medical Research Council Clinical Trials Unit

Website: http://www.ctu.mrc.ac.uk/about_clinical_trials.aspx

For specific information about this project:

Dr Kate Dean (researcher)

Nuffield Department of Medicine
John Radcliffe Hospital
Headley Way
Oxford
OX3 9DU

Telephone: 01865 234940

Email: katherine.dean@ndm.ox.ac.uk

For advice about whether to participate:

Dr Kate Dean (researcher) – as above

9

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals NHS Trust 

Oxford Radcliffe Hospitals NHS Trust Patient Advice and Liaison Service (PALS)

John Radcliffe Hospital
Headley Way
Oxford
OX3 9DU

Telephone: 01865 221473
Email: PALSJR@orh.nhs.uk

The PALS offers support, information and assistance to patients, relatives and visitors. The PALS staff are available to assist with any queries or concerns you may have about the services offered by the Oxford Radcliffe hospitals.

If you are unhappy with the study:

University of Oxford Clinical Trials and Research Governance Office

Manor House
John Radcliffe Hospital
Headington
Oxford
OX3 9DZ
Telephone: 01865 222757

You will be given a copy of this information leaflet and, if you agree to take part in the study, a copy of the signed consent form to keep

10

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC no 10/H0504/62
Patient Information Sheet Interview ORH/Version 4/09/05/2011

Full Information Sheet – Advocate - Interview



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525

katherine.dean@ndm.ox.ac.uk

University Of Oxford Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

Research into Issues Surrounding the Diagnosis of Mild Cognitive Impairment: Family Member / Friend Information Sheet

**Research Ethics Committee: Southampton and South West Hampshire
Research Ethics Committee B**

Study reference number from above REC: 10/H0504/62

Principal Researcher: Dr Katherine Dean

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you may have. This should take about ten minutes. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

Part 1 tells you about the purpose of this study and what will happen to you if you take part.

Part 2 gives you more detailed information about the conduct of the study

Part 1

What is the purpose of the study?

The purpose of this study is to look at the issues surrounding the diagnosis of 'Mild Cognitive Impairment (MCI)' – that is memory problems that are not severe enough to be called 'dementia'. Our present information about what the common problems are and how best to support people with this diagnosis is limited. This information sheet tells you how you can help us increase our understanding and so improve current practice and support.

This study aims to identify the problems that people recently diagnosed with MCI and their family members or close friends have faced. From this information the aim is to develop a 'support programme', for future use in Memory Clinics and to provide better information and support to people diagnosed with MCI and those close to them.

We will be inviting about 50 people to take part in this stage of the study.

1

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940

Fax: 01865 231525

katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

Why have I been invited?

You have been invited because a close family member or friend of yours has recently been assessed in a Memory Clinic or at home and diagnosed with MCI by Prof Wilcock, Dr Stewart or one of their team. They feel that their memory problems may have had an effect on your life and that you might be prepared to discuss this with the research team as part of this study – they have therefore passed this information on to you.

Do I have to take part?

No. It is up to you to decide whether to take part in the study. We will describe the study and go through this information sheet. If you agree to take part you will be asked to sign a consent form. You are free to withdraw at any time without giving a reason. This would not affect the standard of care your friend or relative would receive.

What will happen to me if I take part?

- If you would like to take part you will need to complete and return the enclosed reply form giving your contact details.
- Once we have received your reply form we will telephone you to arrange to talk with you at a time and place that is convenient to you. This could either be at your home, the home of your friend or relative or in the hospital outpatient department. The discussion is likely to take about 1 hour in total.
- We will also arrange to meet with your friend or relative. Unless you both want to be interviewed together we will talk to you separately to make sure that what you discuss with the researcher remains confidential.
- Before starting the interview we will check with you that you understand what taking part in the study involves and ask you to sign a form to say you are happy to do so.

2

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940

Fax: 01865 231525

katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals 
NHS Trust

- The main part of the research involves a discussion with the researcher about any concerns and difficulties you may have experienced as a result of your friend or relative's memory problems and in the process of having them assessed. The researcher will guide the discussion around list of topics but you will be free to add anything that is important to you. The type of subjects that will be covered will include:
 - What changes you noticed in your friend / relative and what problems these caused
 - The experience of assessment of your friend / relative's memory problems by the doctors (if you were present when this took place), both positive and negative
 - How this experience might have been different
 - What information you have received
 - What your concerns are for the future

The discussion should take about 1 hour in total but may be longer or shorter depending on how much you have to say. It will be audio-recorded so that it can be analysed afterwards. The audio-recording will be securely stored and the transcript will be anonymised.

Expenses

If you choose to travel to the hospital outpatient clinic or house of your relative or friend to take part in the study we will reimburse reasonable travel expenses. Light refreshments will be provided in the outpatient department at no cost to you.

What will I have to do?

If you choose to take part in the research:

- Please complete and return the enclosed reply form giving your contact details.
- Once we have received your reply form we will telephone you and arrange a convenient time and place for you to talk to the researcher, you will need to set aside about 1 hour for this

3

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940

Fax: 01865 231525

katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals 
NHS Trust

- You would need to sign a 'consent form' to say that you understand what taking part in the research involves and that you are happy to do so
- You would discuss a range of topics focussing on your relative or friend's memory problems and the process of assessment with the researcher for about 1 hour. This discussion would be audio-recorded.

What are the possible disadvantages of taking part?

You may find it time consuming and inconvenient to arrange and take part in the interview with the researcher. We will try to minimise the inconvenience by arranging the interview at a time and location that is convenient to you. We will reimburse reasonable travel expenses if you choose to travel to the hospital or someone else's house for the meeting.

You may find discussing some of the issues surrounding your relative or friend's memory problems distressing. The researcher will be sensitive to this and the discussion can be stopped at any time if you feel uncomfortable.

What are the possible benefits of taking part?

You may find it helpful to discuss some of the issues surrounding your relative or friend's memory problems that have been worrying you.

We cannot promise that the results of the study will help you directly but the information we get from this study will help improve the support we can provide for people with MCI and their close family members and friends in the future.

What if there is a problem?

Any complaint you have about the way you have been dealt with in the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in Part 2.

4

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940

Fax: 01865 231525

katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals 
NHS Trust

What happens now?

If you have found the information in Part 1 interesting and you are considering taking part in the study, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, including during the interview if you wish. You do not have to give a reason and it will not affect the standard of care your relative / friend receives. Any information collected may still be used but it would not be possible to identify you from this information.

What if there is a problem?

- **Complaints:** If you have a concern about any aspect of this study you should ask to speak to the lead researcher, Dr Kate Dean, who will do her best to answer your questions. She can be contacted on 01865 234940. If you remain unhappy and wish to complain formally about any aspect of the way in which you have been approached or treated during the course of this study you can do this via University of Oxford Clinical Trials and Research Governance office on 01865 222757.
- **Harm:** Given the nature of this study, it is highly unlikely that you will suffer harm by taking part, however if you are harmed by participation in the study, you may have grounds for legal action for compensation against the University of Oxford.

Will my taking part in this trial be kept confidential?

Yes. All information which is collected about you will be kept strictly confidential at all stages of the study. This includes:

- If you agree to take part in the study your name and contact details will be stored securely.
- The interview will be carried out by the researcher in a location where privacy can be assured. You will be interviewed separately from your relative / friend (unless you both request that you are interviewed together) to protect your privacy.

5

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals 
NHS Trust

- Although the interview will be audio-recorded it will be anonymous – you will be given a code to identify you and only the researcher will know this code. It will not be possible for anyone else to tell who gave the answers on the tape once it is recorded. The audio-recording will be stored and transported securely.
- The recording of the interview will be typed out - the person who does this will not know the identity of the person being interviewed in the recording and will be bound by confidentiality regulations.
- The results of many interviews will be analysed together to identify issues that are common in people with MCI. The information will be used to produce a questionnaire which will be sent out to the relatives and close friends of a large number of people with MCI. The results of the questionnaire will be used to produce guidance for Memory Clinics about the best way to support people with MCI and their families and close friends. The results will be published in a journal and possibly on the internet and may be sent out to Memory Clinics across the country. You will not be identified in the published results. When the results are published direct quotations of things that have been said in interviews may be used but once again these will be anonymous and we will not publish any quotations where it would be possible for someone to identify you from what has been said.
- If you join the study some parts of the data collected may be looked at by authorised people to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant. These people may include the sponsor of this research (ie. The University of Oxford), regulatory authorities and research ethics committees including the Research and Development departments at The University of Oxford and Oxford Radcliffe Hospitals NHS Trust.
- Identifiable data about you will not be retained any longer than necessary and will be destroyed by the end of the study (August 2012). Non-identifiable data from the study will be retained for 5 years as per University of Oxford regulations. Paper recorded will be shredded and electronic records wiped by the University's Information Management Service.

6

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940

Fax: 01865 231525

katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals  NHS Trust

Will my General Practitioner be involved?

If an issue is identified during the interview that you or the researcher thinks your GP may be able to help with we will, with your permission, write to your GP about this.

What will happen to the information you collect about me?

Information collected about you, both written and audio-recorded, will be securely stored on NHS or University of Oxford premises. Certain authorised people, who have a duty of confidentiality to you as a research participant, may have access to the information.

At the end of the study information will be stored for 5 years in anonymised form and then destroyed. Paper records will be shredded and electronic data wiped by the University's Information Management Service

What will happen to the results of the research study?

The answers you give in your interview will be analysed along with answers from the other people taking part in the research. In this way common issues faced by people with MCI and their relatives / close friends will be identified. The results will be used to produce a questionnaire about these issues which will be sent out to a large number of relatives / close friends of people with MCI. The results of this questionnaire, and a similar one sent to people with MCI, will be used to produce guidance for Memory Clinics about the best way to support people with MCI and their relatives / close friends. The results and the support document will be published. You will not be identified in any publication. We will send you a summary of the results of the study once it is completed.

Who is organising and funding the research?

Oxford University is organising the study and BUPA Giving is providing funding. The doctor conducting the research is being paid by the University of Oxford, funded by the grant from BUPA Giving, to do so.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed, and given a favourable opinion, by Southampton and South West Hampshire Research Ethics Committee B.

7

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals 
NHS Trust

Further Information and Contact Details

General information about research

INVOLVE

Wessex House
Upper Market Street
Eastleigh
Hampshire
SO50 9FD.
Website: <http://www.invo.org.uk/>
Tel: 02380 651088
Fax: 02380 652885
Email: admin@invo.org.uk

INVOLVE is a national advisory group, funded through the NHS National Institute for Health Research whose role is to support and promote active public involvement in NHS, public health and social care research. INVOLVE can provide information about research and answer any questions you may have.

UK Clinical Research Collaboration

Understanding Clinical Trials Booklet: may be downloaded at
<http://www.ukcrc.org/index.aspx?o=1475>

Medical Research Council Clinical Trials Unit

Website: http://www.ctu.mrc.ac.uk/about_clinical_trials.aspx

For specific information about this project

Dr Kate Dean (researcher)

Nuffield Department of Medicine
John Radcliffe Hospital
Headley Way
Oxford
OX3 9DU
Telephone: 01865 234940
Email: katherine.dean@ndm.ox.ac.uk

For advice about whether to participate

Dr Kate Dean (researcher) – as above

8

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940

Fax: 01865 231525

katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology
John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford Radcliffe Hospitals 
NHS Trust

Oxford Radcliffe Hospitals NHS Trust Patient Advice and Liaison Service (PALS)

John Radcliffe Hospital
Headley Way
Oxford
OX3 9DU

Telephone: 01865 221473

Email: PALSJR@orh.nhs.uk

The PALS offers support, information and assistance to patients, relatives and visitors. The PALS staff are available to assist with any queries or concerns you may have about the services offered by the Oxford Radcliffe hospitals.

If you are unhappy with the study

University of Oxford Clinical Trials and Research Governance Office

Manor House
John Radcliffe Hospital
Headley Way
Headington
Oxford
OX3 9DU

Telephone: 01865 222757

You will be given a copy of this information leaflet and, if you agree to take part in the research, a copy of the signed consent form to keep

9

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Relative Information Sheet Interview ORH/Version4/09/05/2011

Consent Form – Person With Mild Cognitive Impairment– Interview



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford
Nuffield Department of Clinical Medicine
Department of Geratology

John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford University Hospitals 
NHS Trust

Participant Consent Form

Title: Research into issues surrounding the diagnosis of mild cognitive impairment

Research Ethics Committee: Southampton and South West Hampshire
Research Ethics Committee B
Study reference number from above REC: 10/H0504/62
Principal Researcher: Dr Katherine Dean
Study Identification Number of Participant: _____

Please initial box

1. I confirm that I have read and understand the information sheet dated 28/01/2011 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the University of Oxford, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I agree to the interview with me being audio-recorded. ☐
5. I agree to anonymous quotations from things I have said during the interview being used in material published as a result of this study. ☐

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Patient Consent Form Interview ORH/Version1/17/08/2010



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology

John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford University Hospitals 
NHS Trust

6. Should the results of the questionnaire to detect depression suggest I may have symptoms of depression I agree to my GP being informed of this. ☐

7. Should any issues arise during the interview with which the researcher feels my GP may be able to assist with I agree to my GP being informed. ☐

8. I agree to take part in the above study. ☐

Name of Patient	Date	Signature
-----------------	------	-----------

Name of Person taking consent	Date	Signature
----------------------------------	------	-----------

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC Reference 10/H0504/62
Patient Consent Form Interview ORH/Version1/17/08/2010

Consent Form – Advocate – Interview



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford
Nuffield Department of Clinical Medicine
Department of Geratology

John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford University Hospitals 
NHS Trust

Participant Consent Form

Title: Research into issues surrounding the diagnosis of mild cognitive impairment

Research Ethics Committee: Southampton and South West Hampshire
Research Ethics Committee B
Study reference number from above REC: 10/H0504/62
Principal Researcher: Dr Katherine Dean
Study Identification Number of Participant: _____

Please initial box

1. I confirm that I have read and understand the information sheet dated 28/01/2011 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my legal rights being affected. ☐
3. I understand that relevant sections of the data collected during the study may be looked at by individuals from The University of Oxford, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to the data. ☐
4. I agree to the interview with me being audio-recorded. ☐
5. I agree to anonymous quotations from things I have said during the interview being used in material published as a result of this study. ☐
6. Should any issues arise during the interview which the researcher feels my GP may be able to assist with I agree to my GP being informed. ☐

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC reference 10/H0504/62
Relative consent form Interview ORH/Version1/17/08/2010



Dr. Katherine Dean
Clinical Research Fellow
Nuffield Department of Medicine
John Radcliffe Hospital
Oxford OX3 9DU

Phone: 01865 234940
Fax: 01865 231525
katherine.dean@ndm.ox.ac.uk

University Of Oxford

Nuffield Department of Clinical Medicine

Department of Geratology

John Radcliffe Hospital
Headington
Oxford
OX3 9DU

Oxford University Hospitals 
NHS Trust

7. I agree to take part in the above study.

☐

Name of Subject

Date

Signature

Name of Person
taking consent

Date

Signature

Dr Katherine Dean
Southampton and South West Hampshire Research Ethics Committee B
REC reference 10/H0504/62
Relative consent form Interview ORH/Version1/17/08/2010

Appendix 3 – Details of Revisions to Questionnaires Following Focus Group Feedback

Modifications to Questionnaires for the Mild Cognitive Impairment Group

General

- Minor alterations to the wording and formatting were made to make the questionnaires easier to read and complete.
- The wording of the final ‘white space’ question was simplified from *‘If there is anything else you would like to tell us about how your memory problems affect you, or your experiences of healthcare services, please do so here’* to *‘If there is anything else you would like to tell us please do so here’*.

Your Background

- The wording of the introduction was altered to make the explanation as to why demographic information was being collected clearer.
- Question 4: *‘When was your last appointment with the memory clinic / service’*, an option to answer *‘Not Sure’* was added to allow for lack of recall regarding this matter

How Your Memory Problems Affect You

- The wording of the introduction was altered to ask about the last *‘four weeks’* rather than the last *‘month’* for clarity
- Question 11: The wording of the item *‘Worry about feeling generally ‘slowed down’ in both mind and body’* was altered to *‘Worry about feeling generally ‘slowed down’* in order to avoid asking about two separate concepts in one question.
- Question 13: The wording of the item *‘Feeling unable to talk to friends or relatives about your memory problems’* was altered to *‘Feeling unable to talk to friends or relatives about your memory problems because it is upsetting or embarrassing’* to ensure that subjects answering this in the affirmative were describing a limitation with an emotional rather than practical basis
- Question 14: The wording of the item *‘Feeling you have had to cover your memory problems up to hide them from someone else’* was altered to *‘Feeling you have had to cover your memory problems up to avoid upsetting someone’* again, to ensure that the limitation described had an emotional basis.

Your Experiences at the GP and Memory Clinic

- Question 22: *'What made you discuss your memory problems with your GP initially?'* an option for *'If you have not discussed your memory problems with the GP'* was added as a small number of subjects may have been referred to memory services from a source other than their GP.
- Question 23: *'The following questions are about what it was like when you discussed your memory problems with your GP for the first time'* and Question 24: *'The following questions are about what it was like when you went to the memory clinic'* options to answer *'Not Sure'* and *'To Some Extent'* were added to allow for lack of recall and some nuance in responses respectively
- Question 23c: *'Did the GP suggest that your memory problems were 'just due to age?'*, the wording was altered to *'Do you think that your GP took your memory problems seriously?'* to ensure that the concept of the GP being 'dismissive', rather than reassuring, was conveyed
- Question 25: *'From whom do you currently receive practical help and / or emotional support for any difficulties caused by your memory problems?'*, an option to answer *'I don't feel I need any help or support'* was added as this was a common response in the interviews with the MCI group
- Question 27: *'The following questions are about possible changes you would like to see made to the memory clinic in light of your experiences:'*
 - Question 27e: *'Would you have liked to have been assessed using tests that seemed more appropriate for mild memory problems?'*, wording was altered to *'Would you have liked to have been assessed using tests that seemed more appropriate to the nature of your memory problems?'* to avoid the need for subjects to define 'mild' memory problems in order to answer the question
 - Question 27g: A question about improved coordination of services was added to reflect a common topic from the interviews and focus group
 - Question 27i *'Do you feel that there's not much more anyone can do for you at present?'*, wording was altered to *'Do you feel that it is possible for the memory clinic to give you extra help or support at moment?'* for clarity
- Question 28: *'The format of this question, regarding whether a relative or friend was present during assessment of the PWMCI, was altered to make it simpler to progress through the questionnaire'*

SF-12v2

- An introductory statement was included prior to the SF-12v2 to explain the rationale for collecting the information and to encourage participants to complete it even if it did not appear directly relevant to them.

Modifications to Advocate Questionnaires

General

- Minor alterations to the formatting and wording were made to make the questionnaires easier to read and complete.
- The wording of the questionnaire introduction and supporting literature for the PWMCI and advocates was altered to state that the linked PWMCI had been requested to pass on the questionnaire to *'a relative or friend who they think has been affected by their memory problems and who they are in contact with at least twice a week'* in order to ensure that the advocate receiving the questionnaire had sufficient knowledge of the PWMCI to complete it accurately
- The wording of the final 'white space' question was simplified from *'If there is anything else you would like to tell us about how your relative or friend's memory problems affect you, or your experiences of healthcare services, please do so here'* to *'If there is anything else you would like to tell us please do so here'*

Your Background

- The wording of the introduction was altered to make the explanation as to why demographic information was being collected clearer.
- Question 5: *'When was your relative / friend's last appointment with the memory clinic / service'*, an option to answer *'Not Sure'* was added to allow for lack of recall or knowledge regarding this matter

How Your Relative or Friend's Memory Problems Affect You

- The wording of the introduction was altered to ask about the last *'four weeks'* rather than the last *'month'* for clarity
- Question 23: An item about *'loss of the person you used to know'* was added to incorporate a concept that was raised in both the interviews and focus group

Your Experiences at the GP and Memory Clinic

- Question 24 *'What made your relative or friend discuss their memory problems with their GP initially?'*
 - The wording was altered to *'What do **you** think made your relative or friend discuss their memory problems with their GP initially?'* to ensure that the

advocate's opinion is recorded and to avoid appearing to be attempting to verify the linked PWMCI's response

- An option for '*If your relative or friend has not discussed their memory problems with the GP*' was added as a small number of subjects may have been referred to memory services from a source other than their GP
- Question 26: '*The following questions are about what it was like when your relative / friend discussed their memory problems with their GP for the first time*' and Question 28 '*The following questions are about what it was like when you went to the memory clinic*'
 - The wording was altered to '*The following questions are about what **you** thought it was like when your relative / friend discussed their memory problems with their GP for the first time*' and '*The following questions are about what **you** thought it was like when your relative / friend went to the memory clinic*' to emphasise the fact that it was the advocate's experience, rather than the PWMCI's, which was the subject of the questions
 - Options to answer '*Not Sure*' and '*To Some Extent*' were added to allow for some nuance in responses and provide parity with the MCI group questionnaire
- Question 26 '*The following questions are about what **you** thought it was like when your relative / friend discussed their memory problems with their GP for the first time*'
 - Question 26c: '*Did the GP suggest that your relative or friend's memory problems were 'just due to age?'*', wording was altered to '*Do you think that your GP took your relative or friend's memory problems seriously?*' to ensure that the concept of the GP being 'dismissive', rather than reassuring, was conveyed
 - Question 26e: '*Did you feel like you were given the right amount of time with the GP*', wording was altered to '*Did you feel like your relative or friend was given the right amount of time with the GP*' for clarification
- Question 28 '*The following questions are about what **you** thought it was like when your relative / friend went to the memory clinic*'
 - Emphasis was placed on the term '*you*' in several of the answer options to make it clear that opinions on the *advocate's* experience were being sought
 - Question 28j: A question about the length of wait for a follow-up appointment to receive feedback was added to reflect a concern raised in the interviews and focus group


- Question 29: *'From whom do you currently receive practical help and / or emotional support for any difficulties caused by your relative or friend's memory problems?'*
 - For the answer options *'your husband / wife / partner'*, *'other family members'* and *'friends or social groups'* the explanation that *'this may include the person with memory problems'* was added for clarity
 - An option to answer *'I don't feel I need any help or support'* was added as this was a common response in the advocate interviews
- Question 30 *'Which of the following have been helpful sources of information about memory problems?'*, wording was altered to *'Which of the following have you found to be helpful sources of information about memory problems?'* again to place the emphasis on the advocate's opinions
- Question 31: *'If you were present when your relative / friend attended the memory clinic please answer the following questions about possible changes **you** would like to see made to the memory clinic in light of **your** experiences'*
 - Question 31g: A question about improved coordination of services was added to reflect a common topic from the interviews and focus group
- Question 32: The format of this question, regarding whether the relative or friend with memory problems was present during the part(s) of the assessment which the advocate took part in, was altered to make it simpler to progress through the questionnaire

SF-12v2

- An introductory statement was included prior to the SF-12v2 to explain the rationale for collecting the information and to encourage participants to complete it even if it did not appear directly relevant to them. Particular emphasis was placed on the fact that the questions referred to the health of the advocate rather than the PWMCI.

Appendix 4 – Final Versions of Questionnaires

Questionnaire for People With Mild Cognitive Impairment

Questionnaire no: <input type="text"/>
<p><u>EXPERIENCES OF MILD COGNITIVE IMPAIRMENT – Patient Questionnaire</u></p> <p>What is the study about? Researchers at the University of Oxford are investigating the best way to support people with mild memory problems and their relatives and close friends. This questionnaire forms the basis of that research</p> <p>Why have I been invited to take part? As someone who has been diagnosed with mild memory problems we would like your views on your experiences and suggestions for potential improvements to healthcare services. Your participation is, of course, entirely voluntary. Returning the questionnaire means that you understand the purpose of the study and are happy to take part.</p> <p>How do I take part? Please answer the questions in all sections of the questionnaire. This should take no longer than 20 minutes. If you have difficulties filling in the questionnaire please get someone to help you. However, it is <u>your</u> answers we are interested in.</p> <p>To answer a question, please tick the appropriate box. If you make a mistake, cross it out and then tick the appropriate box.</p> <p>What will happen to my answers? The results will be collected by the researchers at the University of Oxford and published in the scientific literature. Your participation is entirely anonymous and the information you give cannot be traced back to you. The number on the questionnaire is for our office use only.</p> <p>Questions or help? Please contact Dr Katherine Dean via telephone on 01865 234940 or via email: katherine.dean@ndm.ox.ac.uk</p> <p>Please return the questionnaire in the enclosed pre-paid envelope</p> <div style="text-align: center;"><p>The logo of the University of Oxford, featuring a circular seal with a book and a crown, and the text 'UNIVERSITY OF OXFORD' in a serif font.</p></div>

Your Background

It is helpful for us to know a little bit about your background so that we can target services appropriately. Please answer the following questions about you.

1. Are you Male ☐
Female ☐

2. What is your age in years?

3. Which of these groups do you consider yourself to belong to?

Please tick only one

- a.** Asian (Indian / Pakistani / Bangladeshi / Chinese / Other) ☐
- b.** Black (African / Caribbean / Other) ☐
- c.** White (British / Irish / Other) ☐
- d.** Mixed ☐
4. When was your last appointment with the Memory Clinic / Service?
- a.** Within the last month ☐
- b.** 2 to 3 months ago ☐
- c.** 4 to 6 months ago ☐
- d.** 7 to 12 months ago ☐
- e.** More than 12 months ago ☐
- f.** Not sure ☐

How Your Memory Problems Affect You

As a result of problems with memory or thinking, how often in the past four weeks have you experienced the following?

Please tick one box for each question

		Never	Rarely	Sometimes	Often	Always
5.	Worry that you have forgotten things such as recent conversations or the names of things or people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Not being able to take part in hobbies or social events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Worry that you have had problems constructing a sentence when talking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Worry that you have forgotten what you had planned to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Worry that you have had problems remembering appointments or important dates, such as birthdays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Worry about a change in your personality	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Worry about feeling generally 'slowed down'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Worry that you have upset other people because of your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Never	Rarely	Sometimes	Often	Always
13.	Feeling unable to talk to friends or relatives about your memory problems because it is upsetting or embarrassing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	Feeling you have had to cover your memory problems up to avoid upsetting someone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	Feeling you have become less independent because you have had to rely on your partner or other people to help you remember things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Irritation or frustration about your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	Feeling worried about your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Feeling downhearted or depressed about your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	Worry about other people's reactions to your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	Worry that your memory problems are more severe than those of other people of your age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	Worry about your memory getting worse in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Patient questionnaire/Version 1/30/09/2011

Your Experiences at the GP and Memory Clinic

The next section of the questionnaire asks about what it was like when you consulted healthcare services about your memory problems, what sort of help and support you have had and your opinions about any changes that should be made.

Going to See the GP

22. What made you discuss your memory problems with your GP initially?

	Yes	No
a. I went to see my GP about something else and the issues regarding my memory were raised	<input type="checkbox"/>	<input type="checkbox"/>
b. I decided to talk to the doctor about my memory because I was worried	<input type="checkbox"/>	<input type="checkbox"/>
c. My family or other people prompted me to talk to the doctor about my memory problems	<input type="checkbox"/>	<input type="checkbox"/>
d. I'm not sure	<input type="checkbox"/>	<input type="checkbox"/>
e. If you have not discussed your memory problems with your GP please tick here <input type="checkbox"/>		

23. The following questions are about what it was like when you discussed your memory problems with your GP for the first time.

	Yes	To some extent	No	Not sure
a. Did the GP act quickly to get things done?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b. Were you confident in your GP's ability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c. Do you think your GP took your memory problems seriously?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Did you feel like you were given enough information about what was happening?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e. Did you feel like you were given the right amount of time with the doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
f. Did the GP answer the questions that you had?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Did the GP or other staff talk in front of you as if you were not there?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
h. Were you given enough privacy when discussing your memory problems?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
i. Would you have liked to be more involved in decisions about your care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Patient questionnaire/Version 1/30/09/2011

Going to the Memory Clinic

24. The following questions are about what it was like when you went to the memory clinic

	Yes	To some extent	No	Not sure	N/A
a. Did you find the tests stressful or upsetting?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
b. Did you have to wait a long time for the first appointment?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
c. If you have had more than one appointment, was the gap between appointments too long?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d. Were you given all the information that you wanted?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
e. Did the staff treat you with dignity and respect?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
f. Before the appointment, were you worried that you might have a more serious memory problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
g. Did the clinic seem well organised?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
h. Did you feel sufficiently involved with decisions about your care?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	
i. Were the results of your tests explained to you in a way that you could understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	

Your Support and Sources of Information

25. From whom do you currently receive practical help or emotional support for difficulties caused by your memory problems?

Please tick all that apply

- a.** Your husband / wife / partner ☐
- b.** Other family members ☐
- c.** Friends or social groups e.g. your local church ☐
- d.** Health or social services e.g. a carer or a support group ☐
- e.** I don't receive any support ☐
- f.** I don't feel that I need any help or support ☐

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Patient questionnaire/Version 1/30/09/2011

26. Which of the following have been helpful sources of information about memory problems?

Please tick all that apply

- | | |
|--|--------------------------|
| a. The memory specialist you have seen | <input type="checkbox"/> |
| b. Other doctors, nurses or healthcare professionals | <input type="checkbox"/> |
| c. Friends or family members | <input type="checkbox"/> |
| d. Specially designed written material such as information leaflets | <input type="checkbox"/> |
| e. 'Traditional' media e.g. newspapers, television and radio | <input type="checkbox"/> |
| f. The internet / world-wide-web | <input type="checkbox"/> |
| g. I haven't received any information about memory problems | <input type="checkbox"/> |

Improvements to Services and Information

27. The following questions are about possible changes you would like to see made to the memory clinic in light of your experiences.

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. Would you have liked to have been given more information at the appointment? | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Would you have liked to have been given more time at the assessment? | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Would you have liked more warning of what was going to happen at the assessment? | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Would have liked the process of assessment to have been shorter? | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Would you have liked to have been assessed using tests that seemed more appropriate to the nature of your memory problems? | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Would you have liked to have had more reassurance from the staff? | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Do you think that your healthcare should have been better coordinated? | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Do you feel that you need any extra help or support from the memory clinic at the moment? | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Do you feel that it is possible for the memory clinic to give you extra help or support at moment? | <input type="checkbox"/> | <input type="checkbox"/> |

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Patient questionnaire/Version 1/30/09/2011

- 28 a.** If a relative or friend **was** present at your memory clinic appointment while you were being assessed, how did you feel about this?

Please tick one box

- | | |
|---|--------------------------|
| Happy for them to be present | <input type="checkbox"/> |
| Would rather they hadn't been present | <input type="checkbox"/> |
| Didn't mind either way | <input type="checkbox"/> |
| A friend or relative was not present while I was being assessed | <input type="checkbox"/> |

- 28 b.** If a relative or friend **was not** present at your memory clinic appointment while you were being assessed, how did you feel about this?

Please tick one box

- | | |
|---|--------------------------|
| Happy that they were not present | <input type="checkbox"/> |
| Would rather they had been present | <input type="checkbox"/> |
| Didn't mind either way | <input type="checkbox"/> |
| A friend or relative was present while I was being assessed | <input type="checkbox"/> |

- 29.** Would you like more information about the following topics?

- | | Yes | No |
|---|--------------------------|--------------------------|
| a. Possible treatments for your memory problems | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Tips on how to get around your memory problems | <input type="checkbox"/> | <input type="checkbox"/> |
| c. The results of the tests you have had | <input type="checkbox"/> | <input type="checkbox"/> |
| d. What you can do to prevent your memory getting any worse | <input type="checkbox"/> | <input type="checkbox"/> |
| e. The causes of your memory problems | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Whether your memory problems are likely to get worse over time | <input type="checkbox"/> | <input type="checkbox"/> |

- 30.** How would you like to be given any extra information?

- | | Yes | No |
|---|--------------------------|--------------------------|
| a. Face-to-face, by a doctor, nurse or other healthcare professional | <input type="checkbox"/> | <input type="checkbox"/> |
| b. In written form e.g. a letter or leaflet | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Via the internet / world-wide-web | <input type="checkbox"/> | <input type="checkbox"/> |
| d. I don't mind | <input type="checkbox"/> | <input type="checkbox"/> |

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Patient questionnaire/Version 1/30/09/2011

NB. At this point, the survey pack also included a copy of the SF-12v2. Due to copyright protection this cannot be reproduced in this thesis. However, the SF-12v2 may be viewed online at this URL <http://www.qualitymetric.com/tabid/238/Default.aspx> (URL published with permission from Optimuminsight Life Sciences Inc, (f/k/a QualityMetric Incorporated)

If there is anything else you would like to tell us please do so here.

Thank you for completing this questionnaire.

Please make sure you have answered all the questions and then return the questionnaire in the pre-paid envelope.

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Patient questionnaire/Version 1/30/09/2011

Questionnaire for Advocates

Questionnaire no:

EXPERIENCES OF MILD COGNITIVE IMPAIRMENT – Relative or Friend **Questionnaire**

What is the study about?

Researchers at the University of Oxford are investigating the best way to support people with mild memory problems and their relatives and close friends. This questionnaire forms the basis of that research

Why have I been invited to take part?

We have asked the person with memory problems to pass this questionnaire on to someone with whom they have regular contact (at least twice a week). As the relative or friend of someone who has been diagnosed with mild memory problems we would like your views on your experiences and suggestions for potential improvements to healthcare services. Your participation is, of course, entirely voluntary. Returning the questionnaire means that you understand the purpose of the study and are happy to take part.

How do I take part?

Please answer the questions in all sections of the questionnaire. This should take no longer than 20 minutes. If you have difficulties filling in the questionnaire please get someone to help you. However, it is your answers we are interested in.

To answer a question, please tick the appropriate box. If you make a mistake, cross it out and then tick the appropriate box.

What will happen to my answers?

The results will be collected by the researchers at the University of Oxford and published in the scientific literature. Your participation is entirely anonymous and the information you give cannot be traced back to you. The number on the questionnaire is for our office use only.

Questions or help?

Please contact Dr Katherine Dean via telephone on 01865 234940 or via email: katherine.dean@ndm.ox.ac.uk

Please return the questionnaire in the enclosed pre-paid envelope



Your Background

It is helpful for us to know a little bit about your background so that we can target services appropriately. Please answer the following questions about you.

1. Are you Male ☐
Female ☐

2. What is your age in years?

3. Which of these groups do you consider yourself to belong to?

Please tick only one

- a.** Asian (Indian / Pakistani / Bangladeshi / Chinese / Other) ☐
b. Black (African / Caribbean / Other) ☐
c. White (British / Irish / Other) ☐
d. Mixed ☐

4. How are you related to the person with memory problems who passed this questionnaire on to you?

- a.** Spouse ☐
b. Son / daughter ☐
c. Other relative (please specify) ☐
d. Friend ☐
e. Professional carer ☐
f. Other (please specify) ☐

5. When was your relative / friend's last appointment with the Memory Clinic / Service?

- a.** Within the last month ☐
b. 2 to 3 months ago ☐
c. 4 to 6 months ago ☐
d. 7 to 12 months ago ☐
e. More than 12 months ago ☐
f. Not sure ☐

How Your Relative or Friend's Memory Problems Affect You

As a result of your relative or friend's problems with memory or thinking, how often in the past four weeks have you experienced the following?

Please tick one box for each question

		Never	Rarely	Sometimes	Often	Always
6.	Worry that they have forgotten things such as appointments, names or recent events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Worry that they have had problems dealing with bills, finances or paperwork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Worry about a change in their personality e.g. they seem more anxious or irritable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Feeling that you are increasingly burdened by having to help out with dealing with bills, finances or paperwork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Feeling that they are less independent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Feeling worried about leaving them by themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Feeling unable to talk to your relative / friend about their memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	Feeling unable to talk to others about your relative /friend's memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Advocate questionnaire/Version 1/30/09/2011

		Never	Rarely	Sometimes	Often	Always
14.	Feeling unsure about whether to try strategies to 'prompt' your relative / friend's memory such as trying to let them remember something by themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	Feeling downhearted or depressed about their memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Feeling frustrated or angry about their memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	Feeling worried, anxious or stressed about their memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Feeling more worried about their memory problems than they seem to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	Feeling less worried about their problems than they seem to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	Worry about the memory problems getting worse in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	Uncertainty about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	Difficulties in your relationship e.g. increased arguments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23.	Feeling that you are losing the person you used to know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Advocate questionnaire/Version 1/30/09/2011

Your Experiences at the GP and Memory Clinic

The next section of the questionnaire asks about what it was like for you when your relative or friend consulted healthcare services about their memory problems, what sort of help and support you have had and your opinions about any changes that should be made.

Going to See the GP

24. What do **you** think made your relative or friend discuss their memory problems with their GP initially?

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. I, or other family members / friends, was worried about their memory problems and prompted them to consult the GP or mentioned it to their GP myself | <input type="checkbox"/> | <input type="checkbox"/> |
| b. They went to the GP about something else and mentioned it then | <input type="checkbox"/> | <input type="checkbox"/> |
| c. They went to the GP about their memory / thinking problems of their own accord | <input type="checkbox"/> | <input type="checkbox"/> |
| d. I don't know | <input type="checkbox"/> | <input type="checkbox"/> |
| e. If your relative or friend has not discussed their memory problems with their GP please tick here <input type="checkbox"/> | | |

25. Were you present when your relative or friend discussed their memory problems with their GP? **Yes** ☐ **No** ☐
*If the answer is 'yes' please go to **question 26***
*If the answer is 'no' please go to **question 27***

26. The following questions are about what **you** thought it was like when your relative / friend discussed their memory problems with their GP for the first time.

- | | Yes | No | Not sure |
|--|--------------------------|--------------------------|--------------------------|
| a. Did the GP act quickly to get things done? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Were you able to talk to the GP about your relative or friend in private? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Do you think the GP took your relative / friend's memory problems seriously? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Was it difficult to talk about your relative / friend in front of them? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Did you feel like your relative / friend was given the right amount of time with the GP? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Did you feel you were given sufficient information by the GP? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Did the GP or other staff talk as if you were not there? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Advocate questionnaire/Version 1/30/09/2011

Going to the Memory Clinic

27. Were you present when your relative or friend attended the memory clinic? Yes ☐ No ☐
If the answer is 'yes' please go to question 28
If the answer is 'no' please go to question 29

28. The following questions are about what **you** thought it was like when your relative / friend went to the memory clinic
- | | Yes | To some extent | No | Not sure | N/A |
|--|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| a. Did you feel the tests were appropriate for your relative / friend's mild memory problems? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| b. Do you feel that your relative / friend had to wait a long time for their first appointment? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| c. If your relative / friend had only one appointment, would you have liked them to have been offered more appointments? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Did you have questions about your relative / friend's care and treatment that remained unanswered? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| e. Did you find any part that you played in the assessments, such as having to 'report on' your relative or friend, upsetting? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| f. Did the clinic seem to be well organised? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| g. Did the staff treat you with dignity and respect? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| h. Did the staff treat your relative / friend with dignity and respect? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| i. Were the results of the memory tests explained in a way that you could understand? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | |
| j. Do you think that your relative / friend had to wait too long for a second appointment to receive feedback of their test results? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Your Support and Sources of Information

- 29.** From whom do you currently receive practical help and / or emotional support for difficulties caused by your relative or friend's memory problems?

Please tick all that apply

- a.** Your husband / wife / partner (*this may include the person with memory problems*) ☐
- b.** Other family members (*this may include the person with memory problems*) ☐
- c.** Friends or social groups e.g. your local church (*this may include the person with memory problems*) ☐
- d.** Health or social services e.g. a carer or a support group ☐
- e.** I don't receive any help or support ☐
- f.** I don't feel that I need any help or support ☐

- 30.** Which of the following have **you** found to be helpful sources of information about memory problems?

Please tick all that apply

- a.** The memory specialist seen by your relative / friend ☐
- b.** Other doctors, nurses or healthcare professionals ☐
- c.** Friends or family members ☐
- d.** Specially designed written material such as information leaflets ☐
- e.** 'Traditional' media e.g. newspapers, television and radio ☐
- f.** The internet / world-wide-web ☐
- g.** I haven't received any information about memory problems ☐

Improvements to Services and Information

- 31.** If you were present when your relative / friend attended the memory clinic please answer the following questions about possible changes **you** would like to see made to the memory clinic in light of **your** experiences.

*If you were **not present** please go to question 33*

	Yes	No	N/A
a. Would you have liked to have been offered practical support e.g. 'home help' or a support group ?	<input type="checkbox"/>	<input type="checkbox"/>	
b. Would you have preferred to complete a different type of assessment e.g. not a 'tick box' form?	<input type="checkbox"/>	<input type="checkbox"/>	
c. Do you think that the communication from the clinic could have been improved?	<input type="checkbox"/>	<input type="checkbox"/>	
d. Would you like to have been given more information?	<input type="checkbox"/>	<input type="checkbox"/>	
e. Would you have liked them to help you talk more openly to your relative / friend about their memory problems?	<input type="checkbox"/>	<input type="checkbox"/>	
f. If your relative or friend had more than one clinic appointment would you have liked a shorter gap between appointments?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
g. Do you think that your relative or friend's healthcare should have been better coordinated?	<input type="checkbox"/>	<input type="checkbox"/>	
h. Do you feel that you need any extra help or support from the memory clinic at the moment?	<input type="checkbox"/>	<input type="checkbox"/>	
i. Do you feel that it is possible for the memory clinic to give you extra help or support at moment?	<input type="checkbox"/>	<input type="checkbox"/>	

- 32 a.** If your relative or friend was **present** at the memory clinic appointment during any part of the assessment that **you** took part in, how did you feel about this?

Please tick one box

- | | |
|--|--------------------------|
| I was happy for them to be present | <input type="checkbox"/> |
| I would rather they hadn't been present | <input type="checkbox"/> |
| I didn't mind either way | <input type="checkbox"/> |
| My friend or relative was not present during the part(s) of the assessment that I took part in | <input type="checkbox"/> |

- 32 b.** If your relative or friend was **not present** at the memory clinic appointment during the part(s) of the assessment that **you** took part in, how did you feel about this?

Please tick one box

- | | |
|--|--------------------------|
| I was happy that they were not present | <input type="checkbox"/> |
| I would rather they had been present | <input type="checkbox"/> |
| I didn't mind either way | <input type="checkbox"/> |
| My friend or relative was present during the part(s) of the assessment that I took part in | <input type="checkbox"/> |

- 33.** Would you like more information about the following topics?

- | | Yes | No |
|--|--------------------------|--------------------------|
| a. Whether your relative / friend's memory problems are likely to get worse over time | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Possible treatments for your relative / friend's memory problems | <input type="checkbox"/> | <input type="checkbox"/> |
| c. What you should be doing to help your relative / friend with their memory problems | <input type="checkbox"/> | <input type="checkbox"/> |
| d. The results of tests taken by your relative / friend | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Other health problems that your relative / friend has that might affect their memory | <input type="checkbox"/> | <input type="checkbox"/> |

- 34.** How would you like to be given any extra information?

- | | Yes | No |
|---|--------------------------|--------------------------|
| a. Face-to-face, by a doctor, nurse or other healthcare professional | <input type="checkbox"/> | <input type="checkbox"/> |
| b. In written form e.g. a letter or leaflet | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Via the internet / world-wide-web | <input type="checkbox"/> | <input type="checkbox"/> |
| d. I don't mind | <input type="checkbox"/> | <input type="checkbox"/> |

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Advocate questionnaire/Version 1/30/09/2011

NB. At this point, the survey pack also included a copy of the SF-12v2. Due to copyright protection this cannot be reproduced in this thesis. However, the SF-12v2 may be viewed online at this URL <http://www.qualitymetric.com/tabid/238/Default.aspx> (URL published with permission from Optimuminsight Life Sciences Inc, (f/k/a QualityMetric Incorporated)

If there is anything else you would like to tell us please do so here.

Thank you for completing this questionnaire.

Please make sure you have answered all the questions and then return the questionnaire in the pre-paid envelope.

Southampton and South West Hampshire Research Ethics Committee B, REC no 10/H0504/62
Advocate questionnaire/Version 1/30/09/2011

**Appendix 5 – Medical Outcomes Study Short Form Health Survey,
12 item version (version 2) Population Norms (Median)**

Scale	Median
PCS: general population	53.03
PCS: 65 – 74 year olds	44.66
PCS: over 75s	39.53
MCS: general population	51.83
MCS: 65 – 74 year olds	54.12
MCS: over 75s	50.87

Table 16. SF-12v2 norms (median) for the 1998 U.S. Population, Standard (4-Week) Form

Appendix 6 – Final Version of the Mild Cognitive Impairment Questionnaire (MCQ)

Outcome Measure for People With Mild Cognitive Impairment

As a result of problems with memory or thinking, how often in the past four weeks have you experienced the following?

*Please tick **one box** for each question*

		Never	Rarely	Sometimes	Often	Always
1.	Worry that you have forgotten things such as recent conversations or the names of things or people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Worry that you have had problems constructing a sentence when talking	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Worry that you have forgotten what you had planned to do	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Worry that you have had problems remembering appointments or important dates, such as birthdays	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Worry about feeling generally 'slowed down'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Worry that you have upset other people because of your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Feeling you have become less independent because you have had to rely on your partner or other people to help you remember things	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

		Never	Rarely	Sometimes	Often	Always
8.	Irritation or frustration about your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Feeling worried about your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Feeling downhearted or depressed about your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Worry about other people's reactions to your memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Worry that your memory problems are more severe than those of other people of your age	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	Worry about your memory getting worse in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing the questionnaire

Appendix 7 – Final Version of the Mild Cognitive Impairment Questionnaire for Carers (MCQ-Carer)

Outcome Measure for Friends or Relatives of People With Mild Cognitive Impairment

As a result of your relative or friend's problems with memory or thinking, how often in the past four weeks have you experienced the following?

*Please tick **one box** for each question*

	Never	Rarely	Sometimes	Often	Always
1. Worry that they have forgotten things such as appointments, names or recent events	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Worry that they have had problems dealing with bills, finances or paperwork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Worry about a change in their personality e.g. they seem more anxious or irritable	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Feeling that you are increasingly burdened by having to help out with dealing with bills, finances or paperwork	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Feeling that they are less independent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Feeling unsure about whether to try strategies to 'prompt' your relative / friend's memory such as trying to let them remember something by themselves	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Never	Rarely	Sometimes	Always	Often
7. Feeling downhearted or depressed about their memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Feeling frustrated or angry about their memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Feeling worried, anxious or stressed about their memory problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Feeling more worried about their memory problems than they seem to be	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. Worry about the memory problems getting worse in the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Uncertainty about the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Difficulties in your relationship e.g. increased arguments	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Feeling that you are losing the person you used to know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for completing this questionnaire

Appendix 8 – Coefficients Generated by Regression Analyses of the Healthcare Experiences Survey Data

Relationship Between Opinions About Improvements to Services and Mental Health

Using SF-12 MCS as the dependent variable

Variable	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	39.924	9.132		4.372	.000
Sex	.919	1.967	.049	.467	.642
Age	.137	.121	.117	1.131	.262
Would you have liked to have been given more information at the appointment?	-3.939	2.704	-.211	-1.457	.149
Would you like to have been given more time at the assessment?	2.023	3.217	.080	.629	.531
Would you have liked more warning of what was going to happen at the assessment?	-3.755	2.533	-.194	-1.482	.142
Would you have liked the process of assessment to have been shorter?	.296	3.637	.009	.081	.935
Would you have liked to have been assessed using tests that seemed more appropriate to the nature of your memory problems?	2.877	2.685	.155	1.072	.287
Would you have liked to have had more reassurance from the staff?	2.846	3.426	.121	.831	.409
Do you think that your healthcare should have been better coordinated?	-7.098	3.057	-.322	-2.322	.023
Do you feel that you need any extra help or support from the memory clinic at the moment?	-5.672	3.400	-.252	-1.668	.099
Do you feel that it is possible for the memory clinic to give you extra help or support at the moment?	-1.504	2.987	-.073	-.504	.616

Relationship Between Opinions About Improvements to Services and Quality of Life

Using MCQ 'emotional effects' scale score as the dependent variable

Variable	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	71.841	19.886		3.613	.001
Sex	.138	4.274	.003	.032	.974
Age	-.579	.263	-.220	-2.199	.031
Would you have liked to have been given more information at the appointment?	13.089	6.197	.315	2.112	.038
Would you like to have been given more time at the assessment?	-5.217	6.813	-.096	-.766	.446
Would you have liked more warning of what was going to happen at the assessment?	1.755	5.503	.041	.319	.751
Would you have liked the process of assessment to have been shorter?	-6.709	7.137	-.097	-.940	.350
Would you have liked to have been assessed using tests that seemed more appropriate to the nature of your memory problems?	3.797	5.924	.093	.641	.523
Would you have liked to have had more reassurance from the staff?	.644	6.858	.013	.094	.925
Do you think that your healthcare should have been better coordinated?	-1.447	6.535	-.030	-.221	.825
Do you feel that you need any extra help or support from the memory clinic at the moment?	.423	7.703	.008	.055	.956
Do you feel that it is possible for the memory clinic to give you extra help or support at the moment?	12.133	6.765	.259	1.794	.077

Using MCQ 'practical concerns' scale score as the dependent variable

Variable	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	66.332	16.126		4.113	.000
Sex	-4.403	3.443	-.130	-1.279	.205
Age	-.403	.214	-.189	-1.888	.063
Would you have liked to have been given more information at the appointment?	6.084	4.913	.184	1.238	.219
Would you like to have been given more time at the assessment?	-.598	5.375	-.014	-.111	.912
Would you have liked more warning of what was going to happen at the assessment?	2.464	4.461	.072	.552	.582
Would you have liked the process of assessment to have been shorter?	-5.717	5.807	-.103	-.985	.328
Would you have liked to have been assessed using tests that seemed more appropriate to the nature of your memory problems?	.616	4.944	.019	.125	.901
Would you have liked to have had more reassurance from the staff?	-4.650	5.580	-.116	-.833	.407
Do you think that your healthcare should have been better coordinated?	7.470	5.311	.193	1.406	.163
Do you feel that you need any extra help or support from the memory clinic at the moment?	1.885	5.971	.046	.316	.753
Do you feel that it is possible for the memory clinic to give you extra help or support at the moment?	7.228	5.313	.192	1.360	.177

Relationship Between Healthcare Experiences Summary Score and Experiences of Individual Aspects of Memory Clinic

Using the 'experiences of healthcare summary score as a dependent variable'

Variable	Unstandardized Coefficients		Standardized Coefficients	t	Sig.
	B	Std. Error	Beta		
(Constant)	-.371	2.430		-.153	.879
Sex	-.485	.433	-.110	-1.121	.268
Age	.015	.030	.051	.498	.621
Found tests stressful or upsetting	.959	.485	.199	1.977	.054
Wait for first appointment too long	-.218	.494	-.047	-.442	.661
Gap between clinic appointments too long	.740	.522	.160	1.418	.163
Given all the information wanted	.781	.593	.171	1.317	.194
Treated with dignity and respect	.326	1.037	.033	.315	.755
Worried before the appointment that problem was serious	.700	.509	.133	1.376	.175
Clinic well organised	-.155	.821	-.020	-.189	.851
Felt sufficiently involved in care	1.490	.615	.283	2.424	.019
Test results explained in a comprehensible way	1.380	.557	.291	2.480	.017